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How Does a Population Residing in a UK Town Perceive Hospice Care Provision? A Qualitative Study of Milton Keynes and its Hospice

Thesis

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How Does a Population Residing in a UK Town Perceive Hospice Care Provision? A Qualitative Study of Milton Keynes and its Hospice

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Dedication

This thesis is dedicated to my parents; my late mother who taught me life can be unkind and unjust, and my father who taught me what love truly is.

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I must finally acknowledge my children Andrew and Cameron in this, who have experienced my educational journey from my undergraduate days, through my masters and now my PhD. You have grown and achieved amazing things as I have progressed. I am so very proud of you both. I hope I have been able to show you that whatever your background, ability, or resources, you can achieve and reach your goals. And it is the journey that makes you who you are, not the result.

Abstract

Hospice care in the UK is a complex service delivered through different streams of provision, managed and funded by independent charities within specific geographical catchment areas. These different service providers provide their own forms of care and support to meet the needs of their local populations. It is known though that hospice care is inequitable. Local and national population demographics including ethnicity and socio-economic background are not reflected in patient statistics. There are gaps in provision for minority groups such as those with learning disabilities, the homeless and those who are incarcerated, and there is a far higher proportion of people with cancer receiving hospice care, compared to those with non-malignant life-limiting conditions. While there has been research attempting to understand and address some of these inequities, there has not been a study which considers this holistically within one local area served by one hospice provider.

This research aimed to uncover how one population perceives and defines hospice care, and how perceptions within that population could influence who they believe should access and receive hospice care. Multiple perspectives have been collated from both patients and non-patients receiving hospice care at the end of their life, organisational staff, and the potential patients of the future – the general public. This combination of data has never been studied collectively from one area before giving a unique insight into the perceived identity of a hospice and the care it provides.

The research found perceptions were highly influenced by the stigma and labelling related to the term hospice as well as of hospice care. Hospice care was confused with the physicality of the hospice building, and there were conflicting views of it being homely and caring, providing an expertise in terms of care but also of being a place of death that was to be avoided. There was significant misunderstanding around when hospice care should be provided, who was eligible for hospice care, and how patients accessed that care and support. This thesis demonstrates the importance of educating not just professionals and patients in understanding hospice care, but also the wider population to help eradicate the stigmatisation and improve knowledge of hospice care to influence people's perceptions and potential use of hospice care in the future.

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1. Introduction

Death, like taxes, is inevitable. The care of the dying has been part of human culture for centuries and has changed over time alongside medical advancements in health care. This thesis focuses on one aspect of that care for the dying known as hospice care. Hospice care, and the institutions wherein it took place, has been a longstanding term and institution in the UK. It derived in the early days from religious orders providing hospitality, to a more health-focused service in the 19thC providing care specifically to people who were dying, to the 20thC with the establishment of the modern hospice movement. This movement soon spread worldwide, and hospice care became a holistic service catering for a dying patient's medical, social, psychological, and spiritual needs (Saunders, 1990).

Currently there are several key issues and debates around dying and care for the dying. Globally there has been increased interest in the equity of care and meeting future needs particularly with trends towards higher demand for palliative care (Sleeman *et al.*, 2019; Larkin, 2019). In the UK there has been drives to improve equity, particularly for marginalised communities (NHS, 2021; NHS, 2016; Hospice UK, 2020). Public health care has pushed for more personalisation and autonomy for patients, and this is also mirrored in care for people who are dying with recognition around people's wishes for the care they want, and the preferred location where they want to receive that care. Within the UK, this has translated practically into a promotion of advance care planning and focusing on the patient preferences on location for care at end of life (Dixon *et al.,* 2019; *NHSIQ*, 2014).

Hospices have historically provided one option for place of care. The ethos and philosophy of hospice care has remained the same since Cicely Saunders' first vision over 50 years ago, but the services currently provided are inequitable, and access variable (Stajduhar, 2020). Provision is heavily skewed towards patients with malignant conditions (Chen, 2019) raising concerns about care for those with non-cancer diagnoses (Cheang *et al.,* 2015). There is also evidence of inequity due to socio-economic status, ethnicity, and disability (Giesbrecht *et al.*, 2018; Markham *et al.,* 2014; Grindrod and Rumbold, 2017). Within the UK we have seen in recent years a growing pressure to adapt and change hospice care to improve that inclusivity

and accessibility to a wider audience (Hospice UK, 2018a). An issue that has always been present, is of a mixed interpretation of what hospice care actually means and how it is defined by a population (Willis *et al.,* 2014). This has impacted not only on practitioner understanding but also that of the wider general public (Cheang *et al.*, 2015; Kozlov *et al.*, 2018). Defining hospice care has been an ongoing issue for hospices, often associated with differences in terminology between health professionals and other stakeholders such as policymakers (Bennett *et al.,* 2010). Therefore, I argue in this research that the definition of hospice care needs to include a broader remit within studies of care at the end of life to not only include patients, but also their communities. This need for a wider sphere influenced the decisions relating to the research question and aims, which I discuss next.

1.1 Research Question and Aims

Research in palliative care needs to include context, culture, differences in practices, and differences in terminology due to the wide variations seen within a population (Timm and Vittrup, 2013). This research investigates this need, that is, the issues around interpretation and understanding of what hospice care actually is through the lens of one local population, in order to address the research question:

 How Does a Population Residing in a UK Town Perceive Hospice Care Provision?

This thesis focuses on a local population within the geographic region of Milton Keynes, a large town in the UK. This geographic area has one provider of adult hospice care, who are the co-funders of this study. The research aim is to uncover how people within that population perceive hospice care and how their perception shapes their beliefs around the care that is provided, who accesses it, and how they access it. This is then discussed in consideration of other research into hospice care, and local and national policy and legislation, in order to consider what if any, action needs to be taken in order to improve not only that perception of hospice care, but the broader issue of inequity within hospice care provision. There now follows a reflective personal background to this research study, followed by an outline of the thesis structure.

1.2 Background to the Research Study

As a mature practitioner with prior experience in several health and social fields, I knew my background was highly influential in my desire to undertake a PhD in this area of public health. The focus on palliative, and specifically hospice care, was less of a concern than my main theme which was equity of care – ensuring a fairness and justice within the care industry so that those in need, receive what they need. I have worked in disability, mental health, and gerontology, and in each sector I have seen examples of unfair and inequitable service provision. All these experiences have shaped my understanding of equity and equality within the health sector and my passion for empowerment and autonomy for patients. As an academic, my background was primarily in education and pedagogy, and the benefits that education can bring not only to individuals, but also to communities and societies. I have developed an enthusiasm and purpose in learning, not only for myself, but also for others. I therefore was very aware of how research could contribute to people's education and learning.

Undertaking a PhD seemed a natural progression for both of these characteristics in order to investigate an area of health care which does have inequity of service provision, to produce new information and knowledge. The intention was that this would add to the growing body of research on hospice care, improve our understanding, and contribute to a wider education and learning on hospice care provision. The decision to research hospice care was decided prior to my involvement as the PhD studentship was co-funded by the local hospice and, therefore, it was a requirement that the research should be connected in some capacity to hospice care. I was fortunate in that the hospice team were very open to the research topic and design being chosen and directed by myself, rather than providing a specific focus for the work. This made it easier for me to consider several different projects during the early stages, before deciding on a local population-focused qualitative study. The reasoning for the chosen topic of the study was primarily due to the hospice not having any prior research involvement or experience. There were no previous studies on this population to draw on, and none could be found within the UK for other populations, and therefore this study has helped to throw light on this unique population through this regionalised qualitative research project.

Embarking on any PhD programme of study is daunting, however, when that study is associated with death, and will involve contact with people who are dying, it naturally can cause significant emotional responses. It made me consider what I knew about dying personally and professionally, and how I would manage potentially emotionally difficult situations during the research. I needed to think about these concerns in order to help balance my research between the acknowledgement of my emotional status and its impact, and the reality and objectivity of minimising bias and partiality in the research (Woodthorpe, 2007). I discuss this further through my reflections in Chapter Six. I now consider the definitions followed for this study.

1.2.1 Definitions

For the purposes of this research, hospice care is being defined in line with the generally accepted hospice philosophy in the UK which states that holistic care is provided by an organisation independent of the health service incorporating physical, practical, social, emotional and psychological care provision (Hospice UK, 2017). In the UK, hospices are part-funded by their local authority health provision, and other funding is sourced through charitable means. It became apparent early on in the research, that defining care terms such as hospice, palliative and end of life care, is both diverse and problematic. This issue is considered in greater detail in the next chapter. However, for the purposes of this research some general parameters were used. Hospice care was considered to be any form of service or support provided directly or indirectly by a hospice for someone who has a terminal illness, or their family/carers. End of life was adopted to mean a person within the last year of expected life, as this is commonly used in medical practice (NICE, 2019) and this was the criterion used for recruitment (see Chapter Five). The term 'professionals' was used to define the organisational staff who worked directly with the public, whether that was in a paid or voluntary capacity. This was to encapsulate the broad range of participants included, in that this went beyond the health sector. The 'general public' was adopted to describe the wider communities within the local population irrespective of status, health or profession. The term 'patients' was used to describe anyone within the last 12 months of expected life as identified

by a clinician, irrespective of whether they were receiving any form of care or support from a hospice or other provider.

1.3 Outline of the Thesis

This thesis comprises 11 chapters. Following this introductory chapter, Chapter Two gives an overview of hospice care within the UK, including the political and charitable contributions to the development and growth of hospices. I then focus on the local geographic area where this study has taken place: Milton Keynes. I give a brief history of this unique locality including an overview of the population demographics. This history also includes an account of the local hospice, Willen Hospice, which is the only hospice that provides adult care for the population studied. Understanding the local population and its hospice is crucial in order to understanding this research, the participants involved, and the data that has been collected and analysed.

In Chapter Three I provide an in-depth review of recent literature relating to this research, focusing on the difficulties in defining care, the inequity of care and the different foci of previous research. This includes consideration of minority groups such as people experiencing homelessness, and those with non-malignant terminal conditions. I also evaluate research which has been undertaken with patients, organisational staff, and the wider general public in order to provide a background to this research; these are also the three cohorts of participants for data collection.

Chapter Four focuses on relevant theoretical concepts that were used during the analysis and discussion of this research. This includes an introduction to the theories of therapeutic landscapes, topophilia and topophobia in relation to hospice care. It also considers the theories of stigma and labelling, how they have been important in healthcare research, and how within health and illness, they have impacted on individuals and societies.

Chapter Five presents the methods employed for this study, and the methodology behind the decisions for research design, data collection and analysis. This includes a consideration of the philosophical approach to the research, the sources of data, the different data collection

methods that were used in this study, the approach to analysing that data, and a consideration of the validity of the research project.

Chapter Six is a reflective account of the research where I consider how the research has impacted on myself as a researcher, and also how I have impacted on the research. I reflect on my own cultural and professional background, the personal challenges I faced during this research as well as the more general research difficulties I encountered throughout the study. This includes issues with the ethical processes, recruitment, data collection and specific participants.

The data is then presented in Chapters Seven, Eight and Nine. Each data source has been considered in detail in a separate chapter starting with Chapter Seven which identifies the findings from the questionnaire undertaken by the organisational staff working locally. This is followed in Chapter Eight by the results from the focus groups with the wider general population and finishing in Chapter Nine with a detailed account of the findings from the interviews with terminally ill patients.

My findings are then considered in more detail holistically in Chapter Ten with an in-depth discussion into the themes identified from the data. These include the perceived provision and need for hospice care, the positive and negative aspects relating to the perceived ethos and culture of hospice care, and access and inclusion of hospice care.

The thesis is then summarised in the concluding Chapter Eleven, which considers how those findings could be addressed within in the local and wider communities. This includes the level of knowledge around hospice care, the labelling and stigmatisation in hospice care, and the unnecessary focusing on physical location, timeframe and eligibility for hospice care. Chapter Eleven ends with a brief consideration of the limitations of this research and possibilities for future research.

A list of appendices and a bibliography which are referenced throughout this study can be found at the end of this thesis. I now begin with an overview of the historical and current context of this research.

2. Historical and Current Context of the Research

This chapter explores the context for this study. The aim of this chapter is to give the reader an understanding of the hospice in Milton Keynes and its place in the wider hospice movement in the UK. The first section focuses on the history of the modern hospice movement within the UK from its inception over 50 years ago and considers how national and local policy and guidance have influenced that growth. The second section focuses on the local community of Milton Keynes, as this is the geographical region for the focus of this study. It has many of the characteristics of any typical British town population but as a designated 'new city'. Its history is unique because it was created from a government directive to create a new settlement in the 1960s, which has impacted on its population growth and diversity. Within this overview of the locality, I also consider the history of hospice care provision and its current provision locally.

As every hospice has its own story behind its creation and development, it is important then to consider the history of the local hospice that serves the Milton Keynes population, which is discussed in Section Three. This will enable a better understanding of its formation and how it became a prominent part of the community. I conclude with a brief description of the referrals received by the local hospice, specifically the data around the types of patients for whom the hospice is providing care, to give a clearer picture of the current situation of hospice care locally in relation to the people that use its services.

2.1 The Creation and Growth of the Hospice Movement in the UK

While it is acknowledged that the term 'hospice' has existed for centuries within the UK, with the original concept coming from the religious orders providing residential hospitality for travelling pilgrims, this has changed and developed considerably throughout history. In the 19th century the focus developed towards practical care for the dying, however still with a very strong focus on religion, residential settings, and social control through the philanthropic structures of those societies. In Victorian UK there was a growth in philanthropy throughout the wealthier classes with a growing concern for the poor and invalid (Graham and Clark,

2008). The most dramatic change in hospice care occurred in the 20th century, and it is this recent history which forms the main focus of this section.

Hospices developed into more secular and medical organisations during the 20th century, and Cicely Saunders is credited with the creation of the Hospice Movement within the UK in 1967. However, she, and others, acknowledged that the original concept and principles for this more modern approach to care for the dying were being discussed from the early 1960s, both in the UK and the USA (Saunders, 2001; Clark, 1999). Saunders, along with other health professionals created the concept of holistic care for patients at the end of life, from their nursing experiences with cancer patients during the 1940s and 1950s. This concept included communication, patient autonomy and control, and supporting death at home rather than at the hospital. This complemented Saunders' own vision – a four-strand approach including expert pain and symptom control, compassionate care, teaching, and research (Murtagh and Larkin, 2013). Her ideas around pain control for patients with cancer demonstrated a shift away from the body and manifestation of disease seen in general medicine, to a focus on the person's lived experience (Seymour, 2012). This developed into the model of caring for 'total pain' which included physical, emotional, social, and spiritual pain experienced by those who were dying, and it became central to the modern Hospice Movement in the UK (Baines, 1990). Her original ideas inspired other professionals and led to the creation of hospices in several countries (Clark,2002).

The birth of the Hospice Movement in the UK at end of the 1960s led to a rapid growth in hospices throughout the 1970s and 1980s. Funding streams became more developed and included a wide range of stakeholders including successive governments, charities and religious organisations. Services became focused on a prognosis-driven service provision, with a diversification of terminal illnesses (Seymour and Cassel, 2017). Alongside this growth was a similar increase in understanding of care at the end of life as a specialism of its own, as it dealt with wider concerns such as dignity and spiritual needs which continued after the cessation of curative treatments. This divergence from clinical practice may appear to show a de-medicalisation of end-of-life care; however hospice care did become a specialised, medicalised environment as the services developed alongside advances in medical understanding and processes (Clark, 2002). The need to care for the dying, from a medical perspective, was clearly there, and the specialism of palliative medicine was first established

in the UK in the late 1980s, as health services, primarily the NHS began to recognise and develop the specialised branch of medicine for the dying (Clark, 2007).

Most hospices were created as private organisations managed separately from the NHS within the UK and, as such, their identity as a business can also be seen, even though most have charitable status (Rahman, 2017). This business approach is evident in the UK in the significant emphasis hospices have on fundraising and commercial ventures. This particular focus on finance is crucial for many hospices for survival, including the local hospice in this study.

Hospices in the UK are unique, individual organisations that have developed and grown in different areas and with different expertise to suit either their community, their workforce, their funders, their trustees or some other internal or external factor, such as other providers of end-of-life care locally. For example, Willen Hospice does not have staff or funding to provide 24-hour care, or a service for children, which is provided by another charity. This has made it difficult to fully understand what hospice care actually is, or could be, within the UK because of the variance in service provision between different areas. Some hospices have initiated programmes to widen and improve their range of services. St Clare Hospice in Essex established support groups for patients with neurological conditions (St Clare's Hospice, 2016). St Christopher's Hospice in London has established a clinical nurse dementia specialist role, whose focus is purely on patients with dementia, and working with care providers to ensure their palliative care needs are met (Monroe and Handsford, 2010). Elsewhere, Royal Trinity Hospice has been developing its services to reach the local homeless population (Royal Trinity Hospice, 2016). However not all hospices have funding or capacity to provide these disparate services.

During their development, hospices have expanded their focus beyond care at the very end of life, that is, the last few days or weeks, to working alongside other medical professionals such as hospital staff and rehabilitation therapists to help people who have been diagnosed with a life-limiting condition over a longer trajectory (Clark, 2002). These diversifications can be seen as further medicalising or professionalising a service in contrast to the original holistic ethos initiated by Cicely Saunders (Cruz-Oliver, 2017).

As hospice care expanded through the UK, there has also been an intensification of focus nationally on better end-of-life care, such as recent campaigns by organisations, for example Dignity in Dying, as well as broader efforts to raise awareness of death and dying by the Dying Matters agenda (Hospice UK, 2018). The UK has also seen the publication of national and regional policy and guidance (NHS England, 2014; NHS England, 2016; National Institute for Clinical Excellence, 2017; National Institute for Clinical Excellence, 2019). These are considered in more detail in the next section on policy and practice.

2.1.1 The Impact of the UK Government on Hospice Care Policy and Practice

Policymakers have increasingly shown an interest in end-of-life care, and the UK government is no exception. Various government documents have been issued which contain standards and guidance on good practice for local authorities, in relation to meeting the needs of people who are at end of life. This section gives a historical overview of that documentation and its influence on the development of end-of-life and hospice care within the UK.

Legislation and policy are particularly important around the legal aspects of death and dying. Within the UK, the Legal Power of Attorney Act in 1971, and then the Mental Capacity Act in 2005 have increased the use of Power of Attorneys, Best Interests Decisions, Advanced Directives, and Do Not Resuscitate orders. Best interest decisions are those made by other people (family, health professional etc) when a patient is deemed to lack capacity to make an autonomous decision due to their age, physical or mental health. An Advanced Directive helps to mitigate the need for best interests decisions as the patient can legally state in that directive what they wish to happen should they become incapacitated at a future date due to a change in their health. Do Not Resuscitate orders can be established for people who do not want any attempt at resuscitation should their breathing and circulation cease for any reason. UK legislation has become an empowerment tool for the individual, in line with the growing social norm of autonomy and individual control in all aspects of people's lives, including death. However, patients may struggle to exercise patient choice and autonomy due to their social context, for example, economic, cultural, or structural factors, and the power imbalances that may be present between patient, carer and organisational staff (Wilson *et al.*, 2013). This is true for all aspects of health care including care at end of life.

A short-lived but important part of the political history of end-of-life care in the UK is that of the *Liverpool Care Pathway*. This was an approach created in 1997 by hospital and hospice staff in Liverpool, to improve care in the last 48 hours of expected life through the adoption of a more personalised pathway for a patient's care. As the pathway developed and expanded throughout the UK it faced growing criticism as it was being used as a decision-making tool. It did not necessarily improve care or patient autonomy, but instead seemed to hastened death, and was finally withdrawn in 2014 (Seymour and Clark, 2018). After the Liverpool Care Pathway was discontinued, a new initiative was launched in 2014 entitled *One Chance to Get it Right*. The guidance detailed key priorities including effective and appropriate communication, decision making, and holistic planning for care. While these were general enough for exploration at any point along a patient's trajectory before death, the wording was aimed at the last few weeks and days of life (Department of Health, 2014). The broad remit of the document is clear as it was written for all health and care professionals, rather than specialists within palliative care settings, indicating a commitment to improving end-of-life care for all and not seeing it as a specialised health care provision only provided by specialist providers such as hospices.

Following consultations and debates on end-of-life care and provision in England, particularly around the inequalities in access to services, the government introduced the *End-of-Life Care Strategy* in 2008. It was the first policy within the UK that promoted good quality care for adults at the end of life, and demonstrated a focus on patient choice and autonomy, with the introduction of advance care planning. The Advanced Care Plan is a comprehensive contract expressing the wishes and feelings of the person completing the plan. The aims of the strategy were to merge several previous initiatives addressing end-of-life care with public health and human rights such as autonomy and patient choice (Seymour, 2012; Seymour and Cassel, 2017).

There have also been legislation, guidance and reports which indirectly relate to end-of-life care. The 2010 *Marmot Review* looked at the inequalities in health within the UK and found that deprived areas of the country experienced lower life expectancies and higher rates of premature death (under 75 years of age), with cancer being the primary cause (Marmot *et al.*, 2010). It identified that improving end-of-life care required a wider societal and economic change. Local communities were also given more autonomy in terms of care provision

through the implementation of the *Health and Social Care Act* in 2012. This included the creation of Clinical Commissioning Groups who are now responsible for allocating funding for local healthcare and hospice provision from the NHS Foundation Trusts.

The *Ambitions for Palliative Care and End of Life Care* was a key government framework published in 2015 and was developed by a consortium of statutory and voluntary organisations to help improve palliative care. The framework detailed key areas or 'ambitions' for development (National Palliative and End of Life Care Partnership, 2015). These covered key aspects such as coordinated care, individualism, and fair access. Ambition Six focused on community-led care which was supported by national and regional charities and organisations including Hospice UK. The National Council for Palliative Care (NCPC) published guidance on Ambition Six to help create and improve partnerships between communities to support them in adopting a public health focus on care at the end of life (Abel *et al.,* 2016). This community-led approach is a distinct change to both the historic and recent progression in the medicalisation of palliative care away from the NHS towards independent specialist care services and hospice settings, a progression which has been suggested as the reason why hospice care has been labelled as both elitist and biased (Willis *et al.,* 2014). Even the role of the specialist nurse has been criticised due to the lack of NHS involvement in regulating and defining the position of Clinical Nurse Specialist. The lack of NHS involvement meant that within the hospice sector there has been a pronounced variance in skills and competency amongst practitioners (Monroe and Handsford, 2010).

This drive for more community-led care demonstrated a change from specialist to generalist and was deemed necessary as professional care was 'struggling to meet the current demands' (Abel *et al.*, 2016: p5). However, a year after the Ambitions framework, the NHS published guidance for commissioners which highlighted specialist palliative care, identifying it as care which provides *"expert assessment, advice, care and support from professionals who specialise in palliative care' for 'patients with more complex or complicated palliative care needs"* (NHS England, 2016: p5). This indicated that, while community care was being promoted, there was still, potentially, this medicalised, professional need for some patients with very complex needs at end of life, to be undertaken by hospices. Therefore, hospices were still important and necessary within local communities. The shift towards community approaches was also indirectly tackling the issue of physical location of care provision, for

example the dominance of the hospice building in providing that care. Halliday *et al.* (2018) posited that public health does not consider the symbolic meanings of places for healthcare as much as focusing on physical and social aspects of care locations. By redirecting that care into communities, governmental policies are helping to redress that symbolic understanding and the perception of hospices being the sole place for care of dying patients.

Policy and practice connected to palliative care can therefore be seen to progress through stages of development, from the early origins of holistic care to an increasingly medicalised and professionalised service directed by government, which is now shifting to a more community focused, social model of care to include the local population it serves, despite recognition that specialised palliative care will need to continue alongside any community-based model. As this thesis involves the population and communities of Milton Keynes, I now focus on that local population. Identifying what specific hospice services are needed locally requires a clear picture of those demographics, and an awareness of the culture of local communities, which are explored next as I consider the background of Milton Keynes.

2.2 The Background of Milton Keynes

This section explores the background of the local area and its population. I firstly consider the historical background of Milton Keynes, its creation and development from a governmental and sociologically informed concept, to becoming an icon of modern city design. I then focus on the health of the local population and how it links with the local demographics, socio-economic backgrounds, and the diverse ethnicity that is present within the population.

2.2.1 The Creation and Development of a New City

Milton Keynes is a new city which was first designated in the UK government *Second New Towns Act 1965.* This legislation permitted new developments to help ease the predicted population growth in the Southeast of England following the baby boom of the 1940s, and a growing influx of migrants. The Act mentioned Milton Keynes alongside other new expansions including Peterborough, Newbury and Telford. The Milton Keynes Development Corporation (MKDC) was created to manage the development and expansion.

The design of Milton Keynes reflected the urban and social changes in that period of history, typifying many of the societal demands such as the need for modern housing and recreation, but also changing economic, social, and technological needs. However, as a new town it also had an individual, progressive style not seen before in the UK, thereby identifying Milton Keynes as both distinctive and yet symbolic of the UK population and society of that time (Clapson, 2004). The style was primarily from the American-based Center for Environmental Studies, which arose out of the Chicago School of urban sociological ideas on how to establish new communities. This was highly influential in the planning of Milton Keynes. The use of their sociological and societal understanding of modernity and future needs of populations encouraged the planning of the city to help improve social interaction and 'balance' for a new generation (Clapson, 2004).

That planning resulted in a uniquely designed environment which differed from the rest of the UK because it deviated from the traditional design and aesthetic appearance used by other towns. One of the planned features of the new city was a dispersed development to suit the growing ownership of cars which had risen steeply during the 1960s, and to reduce feelings of urbanisation and overcrowding (Bendixon and Platt, 1992). The plan stated there would be 'limited' demand for public transport (MKDC, 1970a, p15) as it believed residents would use their own cars, citing that by 1991 it was expected that the average family would own 1.5 vehicles (MKDC, 1970b, p90). It, therefore, placed less emphasis on planning effective and appropriate public transport. This was recognised as a failure by many as it exacerbated feelings of isolation and exclusion among residents impacting on their mental health, and also created issues with accessing health services, such as the hospital and the hospice (Bendixon and Platt, 1992; Clapson, 2004; Popoola, 2008).

The 'new city blues' where residents reported feeling isolated and depressed in newly designed environments, had been identified in other new city developments and was also occurring in Milton Keynes throughout the first decades of development (Bendixon and Platt, 1992). Depression was exacerbated by, but also caused, by family breakdown and financial hardship (Milton Keynes Borough Council, 1991). Both financial hardship and the smaller household sizes resulted in some residents experiencing mortgage arrears and homelessness, causing greater variance in deprivation (Clapson, 2004). The significant changes to housing ownership in the 1980s were reflected in Milton Keynes by the building of larger quantities of

more expensive and profitable private homes to sell rather than rentable properties as had been originally planned (Bendixon and Platt, 1992). This lack of affordable and appropriate smaller rentable homes not only increased levels of deprivation, but also resulted in Milton Keynes being identified in the top 20 cities in the UK for homelessness outside of London (Milton Keynes Borough Council, 1991). Indeed, in 1981 Milton Keynes had an unemployment rate of 10.1% of the population (MKDC, 1981), and house prices were seen to rise by 98% between 1981-1986 (Bendixon and Platt, 1992). By 1991, 44% of people on the housing waiting lists in the local area were homeless, caused by the shortage of appropriate living accommodation to meet the needs of the local Milton Keynes population (Clapson, 2004).

The city was designed for an influx of 250,000 people; the majority were expected to migrate from the densely populated areas of London and the southeast of the UK. Statistics show that 50% of new residents were from London, but also that many migrated from other UK places and 4% from overseas (MKDC, 1970a), indicating a larger than expected minority population. The city plan did briefly mention the need for '*special services and facilities*' to support minority groups to become part of local communities (MKDC, 1970a: p128) but did not go into detail as to what those special services would be and how facilities may be designed or provided. For example, there was little mention in the plan for minority faith groups when it considered the need for and importance of spirituality and religion throughout the development. Indeed, the plan only considered the need for Christian-based church buildings (MKDC, 1970b). This meant that while there may be churches established to provide services such as funerals, other faith communities and their needs were not considered. To support the minority groups the plan vaguely stated:

'The physical and institutional structure of the city will influence the ease and speed of which minority groups can fully share the opportunities open to the majority' *(*MKDC, 1970a: p.10)

Although the plan made little mention of minority ethnic and religious groups it did recognise poverty within the Milton Keynes population:

'It could well be that a relatively small proportion of the population will not be affected by the general advance [in household income] and will grow, not absolutely poorer, but very much poorer in relation to the majority'   (MKDC, 1970a: p.10)

The plan did not state how it would support these lower income families, other than advocating its approach of mixed communities including young families, older people, disabled, those from poorer backgrounds and others from minority socio-economic groups living together. The plan's primary focus was to support the needs of a predominately young working population and their young families. There was considerable emphasis throughout the plan on education, employment, recreation, and social facilities. Even when health was considered, the key aspect discussed was the need for a maternity ward (MKDC, 1970a), although the plan does indicate the use of a community model, and of a community taking ownership of health and wellbeing:

'The city's health service could bring to the city's population a consciousness of its own part in ensuring its general health and wellbeing'   *(MKDC,1970b: p.121)*

While it would not be expected for hospice care to be considered in a local development plan written only three years after Saunders' initial vision for dedicated hospices emerged in the UK, it is notable that this plan did not consider that the population would need a local crematorium and increased cemetery provision. It also did not consider that the population would age, requiring specific services such as caring for people with chronic and life-limiting health conditions.

In the early days of development, Milton Keynes attracted considerable numbers of young people and young families as predicted, and from 2005-2015, Milton Keynes was one of the 20 fastest growing local authorities outside of London (Milton Keynes Council, 2017). However, despite the desire in the plans to create a socially integrated and varied community, it also developed into a middle-class population as there was no provision made for recruitment of people from different classes and backgrounds, and with different employment experience (MKDC, 1970a). It was also seen that some minority groups were tending to settle into clusters in specific localities. Some areas of Milton Keynes became more deprived estates, being primarily populated by families of lower socio-economic status in social housing, with more affluent people being able to choose alternative areas of Milton Keynes (Clapson, 2004). This deprivation, and clustering of residents based on ethnicity or

socio-economic status can still be seen in the population of Milton Keynes today. The current population is therefore the next subject of focus in this chapter.

2.2.2. The Health and Social Demographics of Milton Keynes

The current population of Milton Keynes has health care provision in place for its needs including a main hospital site and several outlying clinics and health centres. It is estimated that the palliative care need in the local area comprises 0.5% of the population, approximately 12,000 people (MKCCG, 2016). This is a figure lower than the national average due to the lower age profile of Milton Keynes. A report by the UK charity Marie Curie has stated that within the UK only 37% of people requiring palliative care are identified by care providers (Marie Curie, 2016) which clearly highlights a need for improved recognition of people at end of life throughout the UK. Failing to identify those potentially in need of care can only become more of a concern for this local area of Milton Keynes as the population ages. Even though the initial residents are now older, the continued significant influx of younger people means the demographics still show a younger population than the rest of the UK.

While death rates are lower in Milton Keynes due to the lower-than-average age of the population, people are still dying. In 2017, 49.4% of deaths in Milton Keynes were in hospital and 10.7% died as inpatients in the hospice (Public Health England, 2017). This rate of death within the hospice is considerably higher than average for hospices nationally in the UK, for which the figure is approximately 5.8% (Public Health England, 2017). However, the hospice has not yet investigated the reasons for this anomaly. One health issue within the city is the connection between health and poverty, which I consider next.

2.2.2.1. Health and Deprivation

Within Milton Keynes there is a wide variance in deprivation. This contributes to its uniqueness as a population as the city has one of the top 20% most deprived populations in the UK; with nine of the 26 local wards shown in the top 10%. This deprivation is linked inextricably to health inequalities and the varied housing within Milton Keynes, as specific

estates with poorer housing are known to access health services far less than people in living in more affluent areas (Scott, 2015). Therefore, it has been suggested that *'tackling housing supply and neighbourhood conditions will help to resolve the social inequalities in health'* (Scott, 2015, p.53). One measure of deprivation is the availability of a car or van for residents. The 2011 census noted that nearly 20% of households had no car or van available. This lack of private transport is especially significant for Milton Keynes because as noted earlier, unlike most other urban developments, the city was designed on the assumption that most people would own and use a car. However, statistically in 16 out of 26 wards within Milton Keynes the number of households not owning a car rises to 30% and these areas also have the highest records of deprivation (Milton Keynes Council, 2013).

The lack of car ownership creates a reliance on a public transport system which is both of poor quality and expensive (Milton Keynes Community Foundation, 2016). Indeed, *'the cost and inconvenience of public transportation… is proving too much for many local vulnerable and disadvantaged people'* (Milton Keynes Community Foundation, 2016, p.15), and it has been recognised that it is challenging to provide an efficient public transport system locally (Milton Keynes Futures 2050, 2016a). Having transport to access health care is crucial not only for general health care needs, but also specific needs such as end-of-life care. The dispersed arrangement of services and facilities in Milton Keynes included centres for health provision. The hospice building is sited in a location that is difficult to access via public transport, potentially impacting on access and inclusion.

Due to the wide variance in areas of deprivation and affluence, Milton Keynes has been described as *'a tale of two cities'* (MK Community Foundation, 2016, p14). There are two markedly different populations and economies. There are higher than average wages in the IT, information and business sectors creating an imbalance with the lower paid service, public and community sectors (Milton Keynes Community Foundation, 2016, p14). Indeed, there has been a persistent concern in Milton Keynes about continued geographic inequalities, exacerbated by some areas recording high numbers of people who have never worked or who are long-term unemployed (Milton Keynes Futures 2050, 2016b).

The recent health profile of Milton Keynes published by Public Health England (2017) stated there is great variance in health resulting in significant inequality in life expectancy locally. The profile evidenced a difference in life expectancy between the most deprived and least

deprived wards in Milton Keynes of over seven years. This demonstrates that deprivation is having an impact on health in poorer areas of the city and suggests that it may be a factor in end-of-life care provision due to the increased rate of early deaths in deprived areas.

This is particularly important as some of those deaths will be due to health conditions where the patient may have benefitted from end-of-life care and support. A recent report by Milton Keynes Council (Scott, 2015) concurred with Public Health England in highlighting the links between deprivation locally and specific health conditions identified as cancer, cardiovascular disease and respiratory diseases (Public Health England, 2017). All these conditions have recognised trajectories in which specialised end-of-life care may be beneficial.

It has also been evidenced that high levels of hospital admissions in Milton Keynes are attributable to conditions caused through lifestyle factors such as smoking and obesity (Scott, 2015), both of which can cause life-limiting conditions. In these conditions, Milton Keynes experienced significantly higher levels than the national average particularly in its most deprived areas. These links with deprivation indicate that work needs to be undertaken to help understand and reduce the inequalities for the most deprived communities in Milton Keynes in all areas of healthcare. However, the recommendations offered in Scott's (2015) report do not include considering improving access or provision for end-of-life care for residents with health conditions such as those addressed above. Indeed, there is no mention of end-of-life care anywhere in the report, and yet clearly the health conditions discussed may well require access to end-of-life care. Aside from socio-economic status there are other factors pointing to marginalised groups which may have an inequity of health service provision and access to healthcare. I will consider briefly one of those groups, that of people experiencing homelessness, in the next section.

2.2.2.2 Health and Homelessness

A key demographic within Milton Keynes is that of homelessness. As mentioned in the first section on the creation and growth of Milton Keynes, homelessness became an issue as the city developed and expanded, especially with house price increases and changes in planning to more privately owned properties and less rental accommodation. The homelessness

problem in Milton Keynes has continued since those early days of development. Government statistics stated that in 2017 there were 227 registered rough sleepers in Milton Keynes (HM Government, 2017). This is an exceptionally high figure when compared to the rest of the UK; only five other areas have higher populations of registered homeless people, with four of those being in London. It is even more concerning that those registered as homeless are considered to represent a small percentage of the true figure. Many are not recognised in official figures such as those sleeping on floors in people's houses or staying in temporary accommodation. In Milton Keynes it is estimated that there are 6.5 homeless households per 100 households, markedly more than the UK average of 2.4 households (HM Government, 2017), confirming that this remains an issue for the city and a significant part of the local population.

As a marginalised group, people experiencing homelessness are often overlooked in palliative care and yet research has shown that the homeless population often experience multiple health conditions, and half are likely to have a physical, intellectual or mental health disability (NHS England 2014). These multiple and sometimes complex health conditions can explain the lower life expectancy rates for people who are homeless. The concept of this population being doubly disadvantaged, that is, homeless *and* dying, was acknowledged by Webb (2015) in her qualitative study. Through her interviews with staff working with homeless people, she concluded that while patients were receiving excellent general support, improvement was needed in collaborative working between health professionals and staff working with people experiencing homelessness who were dying.

Solutions for improving end-of-life care for people experiencing homelessness were considered by Hudson *et al.* (2016) when they undertook a systematic review of qualitative research in this area. They found that there were barriers linked to the challenging lifestyle of homeless people making it difficult for them to access an inflexible mainstream health care system. They concluded that *'great changes will be needed within health care systems to ensure homeless populations have equitable access to palliative care'* (Hudson *et al.*, 2016: p1). They suggested greater support and training for support staff and changing the current health care system to be more flexible and accessible. This challenging lifestyle was also the focus of Giesbrecht *et al.*'s (2018) ethnographic study with Canadian palliative care patients. They interviewed and observed people who were homeless and at the end of life, as well as

their care workers and their informal support networks. The inclusion of informal support networks such as friends of the patients, added considerably to Giesbrecht *et al.'s* research as it widened up the perspective to include people from outside the health care profession and patients experiencing palliative care. They found that due to their structural vulnerability, participants perceived themselves as separate from society and that they did not fit into the recognised health and social environments, similar to Webb's (2015) doubly disadvantaged conclusion three years earlier.

Both Hudson *et al.* (2016) and Stajduhar *et al.'s* (2019) research with the homeless population reported that there was spatial exclusion due to homeless people not having a home where care could take place. They both concluded that such people were disadvantaged in accessing current healthcare settings and processes geographically, economically and psychologically. This means that there needs to be far greater flexibility of service, but also a wider awareness of the possibilities of care provision and locations of that care at end of life. The challenge of providing care for people at end of life experiencing homeless was also noted by Shulman and Hudson (2018) in their qualitative study researching the impact of training for UK homeless hostel staff. They concluded that an improvement in collaboration between the different professionals involved and flexibility in care delivery were required. That collaboration and flexibility would help not only to provide care for those in need, but also improve the understanding of hospice care among the homeless population, the people who support them, and healthcare professionals more broadly. However, it is notable that none of this research included hospice staff to ascertain their perspectives on supporting people experiencing homelessness, whether that be directly, or indirectly through providing training and support to the hostel workers who were the subject of several of the studies examined here.

Most importantly, with the life expectancy of those experiencing homelessness being considerably lower than average, it is surely important to include the perspectives of the wider homeless population on options for care of people who are terminally ill before they themselves may potentially need the service. This voice has been neglected in research, focusing instead on people who are homeless and already recognised as at end of life, and is therefore an identified gap in the research.

An important and integral part of the city has been its hospice, known as Willen Hospice, which has been supported and used by the local population for over 40 years. Therefore the history and development of Willen Hospice is the final topic I consider in this chapter.

2.3 The Background of Willen Hospice, Milton Keynes

Notably in the UK, the planned development of new towns such as Milton Keynes was progressing simultaneously alongside the development of the modern hospice movement, and this included the hospice in Milton Keynes. A Buckinghamshire based GP, Dr Marjorie Reid, understood the importance of considering the needs of dying patients, and produced a report on the topic for a community meeting locally in 1974. The meeting was held by the Christian Council - a body of Christian professionals with varied interests in the developing new city of Milton Keynes. In her report, Dr Reid discussed the need for a *"terminal care home"* to cater for patients who were not being appropriately cared for in the local district general hospital. Reid believed that patients could feel rejected by staff who are interested primarily in those whom they can cure, thereby creating a sense of guilt in patients who do not respond to the curative treatments offered (Reid, 1974). This led to the creation of the hospice in Milton Keynes, now known as Willen Hospice.

None of the early documents from the creation of the hospice specify any life-limiting conditions or focus on cancer, rather they simply support the general ethos of hospice care being available for all who may need it. Reid goes on to describe this holistic care, as advocated by Cicely Saunders, as being care which not only meets medical and nursing needs, but which also enables patients to remain *'mentally alert'* and *'have spiritual care and support for themselves and their families'* (Reid, 1974, p.2). This view was possibly influenced by Reid's visits to other hospices around the UK as she researched the relatively new concept of hospice care.

Reid also acknowledged the specific and unique needs within Milton Keynes due to its geography, economy, demographics and physical environment. This included reasoning that the housing estates were empty during the working day as many people would be away from the home leading to an isolated population and, due to migration into the new city, there would be a tangible distance from family and friends who could have provided support for

people who are dying (Reid, 1974). Also, the new, modern homes often had much smaller bedrooms making it difficult to provide appropriate and adequate care for a dying person (Reid, 1974). These were all concerns that were considered by Reid and the Christian Council, and therefore confirmed to them that there was a need for hospice provision in Milton Keynes.

From the initial discussions held by Dr Reid, a steering committee was formed to direct the creation of the hospice whose stated aims and objectives were: *'to provide and educate others to provide for the physical, emotional and spiritual needs of the dying and their families'* (Jell, 1994. p.2). It was Reid's Christian faith which inspired her, and local district nurse Dorothy Jell to pursue the project of establishing the hospice, originally named The Hospice of Our Lady and St John. It was sited near a religious community called the Society of the Sacred Mission, an Anglican order that had recently moved to Willen village (Milton Keynes Fawcett, 2017). This positioning ensured a Christian ethos permeated the hospice, and assistance from the community was offered in terms of spiritual, financial and practical support. As discussed earlier, there was a focus locally on support for Christians in the establishment of churches and parishes in the development plans, with little regard for other faiths.

Willen village at this time was a traditional, rural village comprising of cottages, farmhouses and a local church in Buckinghamshire. It had been designated as being within the development site for the new city of Milton Keynes. That development included the creation of a man-made lake, an attraction which has since become synonymous with the hospice locally. Originally expected to be a new purpose-built building based in Willen, escalating costs prevented this from taking place as planned and fundraising had to continue, with the religious order significantly contributing to the project. In 1978 an older property in the village became available and was purchased by the Milton Keynes Development Corporation (MKDC) together with a donation from Nashdom Abbey, another Anglican order in South Buckinghamshire (Reid, n.d.), and a loan from the Society for the Sacred Mission.

An undated promotional leaflet called for donations of funds for the development of the hospice in this building and describes the various services that would be available for patients. The key detail to note is that the leaflet does not mention cancer, or indeed any other specific life-limiting condition, but instead referred to people for whom *'curative therapy has nothing*

to offer' (Willen Hospice, n.d.b). Another example can be seen in a published leaflet in 1983, which again described the services provided, requested donations to help fund the work, and detailed potential patients, not by any diagnosis, but as those *'who can no longer be helped in an ordinary hospital'* (Willen Hospice, 1983, p.2), implying a potentially extensive patient base. It is thought-provoking that despite this omission of cancer, whether deliberate or accidental, the reputation and image of hospices such as Willen Hospice became that of a service designed for and delivered to people who are dying of cancer.

In the early years of the hospice, there was significant outreach work to help educate and inform professionals and the community about the hospice and its work. This included meetings with local GPs, health visitors and schools (Reid, n.d). Reid remained heavily involved with the hospice as it was established, later becoming the medical director. The first care provided was the home nursing service in 1979, and this soon expanded to include residential facilities in 1981 and day care in 1986 (Willen Hospice, n.d.b).

Fundraising as a priority continued from the early days throughout the history of the local hospice in Milton Keynes. It started from a project requiring £250,000 to get established in the 1970s, and now has operating costs of £4m a year, only 25% of which is sourced from the local Clinical Commissioning Group (Milton Keynes Clinical Commissioning Group, 2016). Most of the operational costs are funded by private and public donations. This is despite ongoing calls for more governmental funding to support hospice care (Calanzani *et al.*, 2013a). Finances and donation requests were also heavily present in the early literature produced by the hospice itself (Reid, 1974; Willen Hospice, n.d.b, Willen Hospice, 1983). Far less promotional material was produced which detailed the actual work being undertaken by the hospice. This pattern appears to still be consistent today with either printed or online materials focusing primarily on fundraising activities, goals and achievements (Willen Hospice, 2017). The first local charity shop was opened in 1988, and in 1990 the hospice launched its trading arm – Willen Hospice Ventures – to meet the high and escalating costs with maintaining and developing the hospice. The fundraising provided a form of awareness raising about the hospice's existence locally, and its need for ongoing financial support.

The development and growth of Milton Keynes caused concern within the hospice in relation to capacity to meet future demand, and by 1989 it increased inpatient beds from 11 to 25 (Willen Hospice, n.d.a). Later in 1998, the hospice developed a new Hospice at Home service

and reduced inpatient services to its current provision of 15 inpatient beds. Even with this reduction in inpatient beds, it is interesting to note that 11% of local deaths recorded in Milton Keynes occurred at the hospice in 2017, compared with only 4.5% nationally (NEOLCIN, 2014). This is consistent with a trend for a high percentage of hospice deaths in previous years, demonstrating a unique popularity of the hospice locally.

Until this research there has been no collation and cataloguing of data relating to who was using the hospice. There has been no evaluation relating to the referrals and admissions at Willen Hospice for any research or audit purposes. The only available data in relation to these issues comes from national reports and statistics. However, these cannot be assumed to be comparable to the situation within Milton Keynes because of the variances in the population discussed in this chapter, and in particular the anomaly of the high number of inpatient hospice deaths. As explained in the section on the growth and development of hospice care, each hospice has its own history, which demonstrates a progress of development that varies between hospices. This individualised history, together with the previously explained uniqueness of the city, would therefore advocate a cautious approach to assuming a national picture from the UK is synonymous with the situation locally. One of the ways in which hospices differ can be explored by examining the referrals that are received which indicates the patients who are supported. The next section discusses the current hospice care provision and reports on the details of three months of patient referrals for Willen Hospice.

2.3.1 Current Hospice Care Provision and its Referrals

As mentioned in the previous section, there has been no previous investigation into the numbers of patients who have used this hospice locally. In order to research the perceptions of hospice care, a clear understanding is needed first of the hospice itself and the patients currently being referred to the service.

The hospice is a very well-established charity locally, providing outpatient and inpatient support to referred patients, as well as working alongside professionals in other settings including the hospital and residential care environments. The hospice also has a growing educational programme, providing training for health care staff from all sectors locally and trainee positions for nursing and medical students. Their main provision is hospice care within

people's homes, accounting for a significant proportion of their work. This involves nursing staff attending patients and supporting families within the home setting. Within the hospice building various alternative therapies are offered, and there is a well-established outpatient facility used by patients at various times throughout the day. The lymphoedema service provided by the local CCG is also based at the hospice site, and patients attend the clinic for treatments.

The building has capacity for inpatients who are primarily admitted for pain management and symptom control as well as care at the very end of life when needed. The hospice also provides support on site for families and carers who can attend support sessions and private counselling, and the site has a training and education suite for the courses they provide to health professionals. Regular events are held at the hospice site, primarily around memorial days for families, and it has a prominent place beside a lake in a popular recreational parkland area. Volunteers are used extensively within the building and local area arranging events such as walks and social sessions for patients and carers, quiz evenings, and other charitable and fundraising activities.

Locally, the hospice is a central part of many organisations, being their chosen charity for fundraising, and the hospice itself runs several events throughout the year for fundraising which are very popular and well supported by the local communities and media. This has enabled it to become well known as a charity, although that focus is often on the financial need of the charity rather than the services it provides (Willen Hospice, 2017).

As this qualitative study is focusing on people's perceptions of hospice care, it is important to understand who is currently using the hospice, that is, who is being referred to their care. In order to achieve this, statistics were requested for a three-month period from January to March 2018. This section focuses on that data. The hospice provided anonymised details for every referral, totalling 312 patients. These are detailed below, together with a short discussion about how they relate to this study.

The hospice used their own records to source this data from referral forms received into the office for input into a secure electronic database. To obtain the data for this research, it required a member of staff to access the referral records, anonymise the data and provide them for this study in the form of a spreadsheet. The data supplied included age, gender,

primary diagnosis, the referrer, and the GP practice of the patient. Data about ethnicity and religious background was incomplete for significant numbers of referrals and therefore has been omitted. This in itself was useful however, as it enabled the hospice to consider more carefully the data it requires during the referral process, and how they can improve to ensure they keep more accurate records. It is known that patients from BAME groups are less likely to access hospice care provision (Markham *et al.*, 2014) so hospices need to record this data to ascertain their own situation, and to enable them to address any inequities. There now follows the data that was extracted:

Table 1: Patient Gender of Hospice Referrals

Gender	No. Referrals
Male	148
Female	164

As can be seen, there is a difference in the gender of referred patients, a divergence of 9%. The higher number of female patients may be attributable to the slightly higher number of women of older ages due to a higher life expectancy of women as compared to men. It could also be attributable to possible wider acceptance among women about seeking healthcare when in need (Hawkes and Buse, 2020). This research was not focused on investigating that further, but it is useful to acknowledge the higher proportion of female patients.

The primary diagnosis of referred patients is significant, as seen below:

Table 2: Primary Diagnosis of Referred Patients

Primary Diagnosis	No. Referrals
Cancer	247
Organ Failure	25
Neurological	14
Dementia	7
COPD	5
Pneumonia	3
Frailty	2
Multiple Sclerosis	1
Sepsis	1
Unknown	7
TOTAL	312

This data demonstrates the exceptionally high prevalence of cancer, a commonality the local hospice shares with the national picture of cancer being the most dominant reason for referral. Here, it comprises 79% of the total (247 out of 312 referrals). Nationally, cancer accounts for around 29% of deaths (National Council for Palliative Care, 2015), and a similar figure is seen locally of 28% (NEOLCIN, 2012). However, there is a higher-than-average number of deaths locally either caused by or with an underlying cause associated with respiratory disease (NEOLCIN, 2012). This difference is not reflected in the referrals to the hospice for people with such conditions, highlighting an issue of hospice patients not representing the localised reality of those with life-limiting conditions who may need palliative care. There is a demand for care at end of life from patients with other non-malignant conditions, indeed most people with a life limiting condition including organ disease, dementia and neurodegenerative disease will need some form of end-of-life care during their final years (Marie Curie, 2016). The referrals data here demonstrates that cancer is still the main reason why people are being referred for hospice care, raising questions of why other conditions are less represented; a question which will be discussed further in this thesis.

The age of patients is considered below:

Table 3: Age of Patient at Referral

Age	No. Referrals
18-29	1
30-39	5
40-49	18
50-59	40
60-69	74
70-79	69
80-89	79
90+	26
TOTAL	312

Over 100 referrals a month came through to the hospice during the three months that were collated for this research. Of those, it is noticeable that a significant proportion of the referrals

are for older people, with over half the referrals relating to patients over 70 years of age, and only 8% for patients under 40. It is difficult to compare the referrals for this one hospice to the national statistics as there is little national data available, and the data that is available tends to be based on estimations made from incomplete data (Hospice UK, 2017). This again highlights a gap in knowledge that needs to be addressed. Records of who is accessing hospice care nationally are essential to help highlight areas of inequity of service, for example, across different generations of patients requiring hospice care. As discussed in this chapter, the local population is currently experiencing an ageing of the original residents of the new city and this 'bubble' may well be impacting on the age of patient referred

It is also important to know where referrals to hospice care originate, which is shown below:

Table 4: Referrer of Patient for Hospice Care

Referrer	No. of Referrals
Palliative Care Hospital Team	150
GP	120
Other Hospital Team	41
Care Home	1
Total	312

All referrals to the local hospice have come from a health care professional, primarily the hospital team or a GP. However, referrals could, and arguably should, come from any source including self-referral which is not apparent in this data set. Not all patients may have clear access to medical support and intervention for various socioeconomic reasons such as the significant homeless population. Clearly, the majority of referrals would come from a palliative care specialist at the hospital as they are connected with patients at end of life every day in their role. However, not everyone who is at end of life is known to that hospital ward. One reason may be because in Milton Keynes hospital, this ward is known as the 'Macmillan unit' because of the links with the Macmillan charity; a specialist charity in the UK that supports people with cancer. Patients, therefore, have a primary diagnosis of cancer. People with other life-limiting conditions would not necessarily attend this unit, and therefore not

come into contact with the professionals who are referring most patients to the hospice in the numbers evidenced here. There is also a concern that not all patients with cancer would necessarily be known or attend the Macmillan unit.

It is also particularly surprising that only one referral came from a care home environment. As the majority of care home residents are elderly, it might be expected that their likelihood of being at the end of life due to life limiting conditions would be much higher, and therefore they might have a greater likelihood of requiring hospice care. While it can be argued that staff within care home environments, particularly those designated for older people, should have some expertise in end-of-life care, it has been suggested that there are still issues around care home residents receiving appropriate care at the end of life (Finucane *et al.,* 2013) and hospice involvement with residential and nursing care homes is one area in which they have been developing. There is also a glaring gap in the lack of any self-referrals or referrals from non-medical professionals such as social care workers or from the charitable sector. Therefore, from this data alone, possible reasons for the predominance of cancer referrals can be seen, and questions raised about why other sources of referrals are not occurring, including self-referrals.

This chapter has explored in detail the background and history of the modern hospice movement, the city of Milton Keynes and its population, and the local hospice serving that population. I have brought these three areas of historical context together to highlight the development of hospice care and the demand within the local area. I have detailed here how the history of Milton Keynes and its population has affected the epidemiology of the local area, including that relating to terminal illness. I have also evidenced the current situation in relation to the use of hospice care locally through an explanation of the patient referrals into the service. The amalgamation of these varied but inter-related areas of interest have helped to situate this research and the need to better understand how a population currently perceives its hospice care and the role of a hospice. The next chapter explores previous research connected to end-of-life, palliative and hospice care, in order to demonstrate the gap in knowledge that this study addresses.

3. Review of Current Research Relating to Hospice Care Provision

The previous chapter outlined the history of hospice care in the UK and the influence of policy on the growth of hospice provision and a background of the local area where this study took place as well as documenting the growth and development of the local hospice care provider serving that area. Over the five decades since the start of the modern hospice movement, there has been growing research into hospice care provision within the UK and internationally, particularly as the development of services has expanded across the world. This chapter explores some of the key research in more detail.

This review adopted an iterative process, with literature being sourced throughout the research. This was due to the open-ended approach of the study in that initially there was no clear identifying research topic; after ethical approval a clearer focus was determined looking at how hospice care was perceived by different stakeholders, and during the data collection and analysis stages, new areas of interest were included such as the use of geographical theory and the inequity of care for people experiencing homelessness. Literature was identified through searches using a university search engine which pooled several literature databases into one searchable catalogue. Key terms relevant to hospice care, community perspectives, access and inclusion were used to source potentially appropriate studies. These were then reviewed to identify current issues within hospice care research, and research more generally into care at end of life. The first analysis of the literature identified the lack of clarity in the definitions of hospice care.

Here then, in the first section, I consider how such definitions are contested. I focus on the arguments which suggested there is a lack of clarity and difficulty in defining when a patient is dying, but also the confusion in defining hospice care, palliative care and end-of-life care, terminology that was often used interchangeably. Later in the research, the importance of communities and the various 'voices' within those communities became a dominant topic, which then demanded another review of literature focusing on this aspect. The second section of this chapter discusses how qualitative research has contributed to an understanding of the perspectives of patients who are dying, which I then develop in the third section to consider the wider general public's understanding of care for terminal illness. This includes consideration of marginalised communities such as those experiencing

homelessness, when the opportunity arose during the data collection stage to include this perspective through engagement with this local population.

3.1 The Difficulties in Defining Dying

The difficulty in defining dying and the care of people who are dying is not an issue exclusive to the UK. It was identified as a global phenomenon by Lynch *et al.* (2013) in their study which mapped palliative care development worldwide. They noted that quantifying global levels of palliative care was hindered by the lack of uniformity in understanding the terminology used by health professionals. It is also impacted on by the different understandings of the term 'care'. This can be seen as the care delivered practically to a patient, but also the more abstract caring about a patient, that is, the social, emotional and psychological aspects of care (Milligan and Wiles, 2010). This is an important consideration particularly when thinking of end-of-life care generally, and hospice care specifically, as both evoke emotional responses about the care received, and the carers who deliver that support.

In this section I consider how the terminologies of hospice care, palliative care, and end-of-life care are defined and understood through the research that has been undertaken in those fields. These are presented in separate sections within this chapter, but firstly I want to consider the issue of knowing and defining when a patient is dying.

3.1.1 Defining When a Patient is Dying

Identifying when someone is actively dying can be challenging, not least because acknowledging someone is dying is accepting that, medically, the patient is no longer curative. This means the patient is no longer aligned with the medicalised goals of removing illness and restoring good health, which are often the accepted purposes of healthcare (Montgomery *et al.*, 2017). Defining when a patient is dying is therefore an issue recognised by many including Cicely Saunders (1990), the founder of the modern hospice movement in the UK.

This issue was also identified in a methods review commissioned by NHS England, where they expressed concern that professionals and care home staff continue to find the dying stage of

life difficult to identify (Goodman *et al.,* 2012). Knowing when someone is actually dying is significant as Izumi *et al.'*s (2012) investigation into the definitions of end-of-life care, hospice care, and palliative care highlighted. They found that a poor understanding of the definition of care for terminally ill patients led to a lack of accurate identification of who was dying, and thus prevented access to appropriate care. They suggested that to help identify when someone is dying, rather than favouring a primarily biomedical model of assessing current illnesses and predicted life expectancy, professionals should focus instead on the person's outlook on life and broader nursing needs. This would include whether the patient actually perceives themselves to be dying (Izumi *et al.*, 2012). However, the definition of care at end of life that they proposed, appears too vague to be of practical use:

'to assist persons who are facing imminent or distant death to have best quality of life possible till the end of their life regardless of their medical diagnosis, health conditions, or ages.'

(Izumi *et al.,* 2012: p616)

Izumi *et al.'*s phrasing is difficult in itself to define as quality of life is subjective to the individual conditions and stating *'imminent or distant death'* is impossible to quantify. This offers a large timeframe of potentially years or decades. Timing is therefore a key issue in defining dying and is discussed in the following sections in relation to identifying palliative, end-of-life care and hospice care. These terms can sometimes be confused or used interchangeably, and there is also a tension around the use of language associated with death and dying that can be used by practitioners in potentially difficult emotional conversations with patients (Hawley, 2017). The next three sections consider those terms and how they may be defined, starting with hospice care.

3.1.2 Defining Hospice Care

The definition of hospice care is strongly associated with Cicely Saunders, and her holistic philosophy has become ingrained within modern hospices today (Willen Hospice, 2016). Saunders' definition of hospice care was to adopt an approach that used the concept of 'total pain' comprising four elements: physical, psychological, social, and spiritual. These underpin

hospice values in supporting patients to achieve a good death and are often cited in definitions of hospice care (Hospice UK, 2017). Of these four elements, the least studied or evidenced in practice is that of spiritual care, and yet it is strongly connected to the origins of the hospices. Saunders was an active Christian and openly acknowledged the Christian background to hospice care, linking it with both the linguistic heritage of the word 'hospice' and how the Christian ethos influenced the early hospitals in contrast to Hippocratic traditions of removing illness and providing healing (Saunders, 2006). Despite this, Christian aspects of hospice care have since been removed from definitions. Many hospices now favour more generalised terms such as 'spiritual needs' as seen in definitions published by the National Council for Palliative Care (NCPC, 2015) and the World Health Organisation (WHO, 2017). The ongoing need for spiritual care has been evidenced in research, showing the benefits and importance of including people's spiritual needs and beliefs, in both decision making and delivery of care (Lan Fang *et al.*, 2016; Abudari *et al.*, 2016; Blank, 2011). Whether spiritual needs are still viewed as 'paramount and very prevalent' (Saunders, 2006, p.256) within hospice care is not clear. Certainly, the physical, psychological and social aspects of hospice care are still important and present in modern day care.

Hospices are often perceived as offering high quality care and treatment which is superior to hospitals (Willis *et al.,* 2014). This popular belief is possibly held because a hospice is also viewed as somewhere which is more like home, and a more desirable alternative to hospital (Higginson *et al.,* 2013), thereby incorporating '*the best elements of the home setting and hospital medical care*' (Nebel-Pederson and Emmers-Sommer, 2012: p420). Similarly, a literature review by Rigby *et al.* (2010) found that for older people at end of life residing in hospices, care homes or hospitals, there was a desire and impetus to make their environments more homely through the use of personal items, keepsakes and artwork.

Apart from the holistic nature and homeliness of hospices, hospice care can also be defined by life expectancy. Stone *et al.* (2012) argued in their review into hospice provision within prisons in the US and UK, that hospice care was for any patient with less than six months life expectancy. Their review also demonstrated how terms are used interchangeably as the authors use hospice in their title, end-of-life care in their introduction and palliative care in their research aim, indicating either an acceptance of the equality of the three terms, or a confusion about any similarities and differences. Mixing terminologies aside, there can be a

real impact on understanding hospice care if prognosis timescales are considered an eligibility criterion for that care. Izumi *et al.* (2012) discussed earlier tried to redefine care at end of life to be for potentially anyone with a terminal condition, irrespective of how long their prognosis is. They conceded, however, that currently in many countries including the USA, Japan and Canada, a six-month prognosis was required to be eligible for hospice services, and a timeframe is often used worldwide as a criterion for hospice care. It is not yet known how embedded this use of a prognostic timeframe is, not just in practice, but also in the culture and understanding of patients, practitioners and wider societies when considering care at end of life.

Another aspect that can be used to define hospice care can be the primary terminal condition of the patient. The focus on cancer in hospice care was noted by Gattrell and Wood (2012) who argued that most hospice and specialist palliative care services are used by cancer patients. Research that focuses on hospice care provision for cancer patients (Currow *et al.*, 2020; McCaughan *et al.*, 2019; De Vries and Plaskota, 2017) perpetuates the myth that hospices are primarily eligible for use by patients with cancer and this is a point supported by Willis *et al.* in their 2014 commentary on specialist palliative care services. Therefore, research in hospice care needs to expand beyond cancer to consider other terminal conditions that it can support.

This prevalence of cancer within hospice care is also discussed in condition-specific research with non-cancer patients that has been undertaken. Hayle *et al.*'s (2013) qualitative study involved interviews with patients with chronic obstructive pulmonary disease (COPD) accessing specialist palliative care which included hospice care. They found that as services were initially designed for malignant conditions like cancer, there was poor access for patients with non-malignant conditions such as COPD. Cheang *et al.* (2015) also highlighted this concern in relation to heart failure when they surveyed professionals including hospice staff and noted a lack of care provision for patients with heart failure in the UK. As a consequence, there was an unmet need and underutilisation of care for patients with this condition.

To address this disparity, Willis *et al.* (2014) advised access to care should be based on complexity of need, rather than biasing towards any particular diagnostic condition. They argued that, since UK hospices are charitable organisations, they can ultimately decide who

they care for, which they perceived may offer some reasoning as to why there is such a large bias towards cancer patients within hospice care. The lack of current provision of hospice care for patients with non-cancer conditions, may, however, be influencing perceptions and utilisation of hospice services, creating a continuance of the cancer bias. Therefore, there is a need to uncover these perceptions to ascertain if and how these impact on people's understanding of what health conditions hospice care can support.

Hospice care may also be defined by the ethos and philosophy that surround that care. This view was reflected by Moore *et al.* (2013) in their phenomenological research into hospice care provision, where they found the ethos helped to define hospice care as an approach, rather than a building. The charity Hospice UK, which directly supports UK-based hospices, also promotes this notion of a hospice being more than just a building (Hospice UK, n.d.). However, this redirection of the definition of hospice care needs to be understood by the wider population rather than just the hospices themselves, in order to improve equity and inclusion. This is especially true as it is yet to be demonstrated how far this perception reaches into our communities. Other researchers have noted similar findings. Nebel-Pederson and Emmers-Sommer's (2012) study identified that for patients utilising hospice care in the USA, there was a disparity between the holistic approach promoted by the hospice and the patients' views. Rather, the patient perspective was more aligned to biomedical concepts of pain management and medication, rather than any holistic understanding of care.

It is questionable whether the general population of the UK may view the term hospice in this abstract and philosophical way as an ethos or approach or concur with that evidenced with patients in Nebel-Pederson and Emmers-Sommer's study, in seeing hospice simply as a physical place where people go to manage their death. Of course, the term care itself can be seen as an abstract concept in terms of both what is delivered and how it is delivered (Milligan and Wiles, 2017), linking in with this notion that hospice care is more than the practicalities of the services they provide, but the ethos and culture around that delivery. What Nebel-Pederson and Emmers-Sommer's research demonstrated was a reluctance by some hospice users to accept the philosophic and holistic definition of hospice care, concluding patients preferred a more reductionist medical model that focused on their condition and physical treatments. Their research however did not go beyond investigating this disparity of understanding of hospice care beyond the patients using that provision, so the view of the

general public of health care professionals was not considered. Their finding from patients associated hospice care with the physical place to receive care, and place of death could be because of the word 'hospice' itself, which can be understood as the name of the building itself, that is, the hospice.

The terms palliative care and end-of-life care do not have that connection with a physical setting but are heavily used alongside and interchangeably with hospice care. The next sections discuss how palliative care and end-of-life care may be defined.

3.1.3 Defining Palliative Care

Some palliative care organisations and researchers use the palliative care definition taken from the World Health Organisation (Goodman *et al.*, 2012; Milton Keynes Clinical Commissioning Group, 2016). This definition explains palliative care as a holistic approach to improve quality of life through the physical, psychosocial and spiritual needs of the patient and families involved (World Health Organisation, n.d.). This clearly shows links with Saunders' original philosophy of hospice care as mentioned in Chapter Two. In their critique of palliative care, Randall and Downie (2006) offered some challenging views on what palliative care is and should be. This included their belief that the definition has *"deep rooted attitudes"* which determine care provision and practice (2006, p.4) rather than any adherence to a standardised definition. I question whether such attitudes have changed, or if these underlying perceptions persist about care for terminally ill patients and their families.

The General Medical Council (GMC) published guidance in 2010 for medical professionals in which their glossary states that palliative care *'is not dependent on diagnosis or prognosis and can be provided at any stage of a patient's illness, not only in the last few days of life'* (General Medical Council, 2010, p.88). The GMC definition has a wider timeframe that resonates with that of Izumi *et al.* (2012) earlier when trying to define when someone is dying. The timeframe is a key issue as time is often used as an identifier for the provision of specialist care for people who are dying. However, palliative care is often seen as a generic term defining the care offered from diagnosis and *'even before a patient enters the terminal stage of their illness'* (Izumi *et al.,* 2012: p.612). This definition differs from the understanding of the term Specialist

Palliative Care (SPC), which within practice is often linked to the work of specialist hospital units and hospices (Willen Hospice, 2016). SPC has been defined by NHS England as services for people with *'more complex or complicated palliative care needs'* (NHS England, 2016). This can include the holistic elements of physical, social, psychological, and spiritual needs, which could therefore blur in terms of what the specialism actually is, or indeed if it is just another name for hospice care provision. The definition of this specialist service also leaves open the question of how people are now being identified as being eligible for a more specialised service, over and above their current palliative care needs, causing a potential bias in hospice care (Willis *et al.*, 2014).

The wider timeframe used by the GMC to reduce the focus on care at end of life as a definition of palliative care can therefore cause further confusion when patients are referred to end-of-life care provision, a term often used in clinical contexts as well as within local and national guidance, policy and legislation. Therefore, this term of end-of-life care is considered next.

3.1.4 Defining Care at End of Life

UK government literature has very little clarification of the term 'end-of-life care'. For example, in the 2016 UK government policy release on their commitment to end-of-life care, there is an implied understanding of end-of-life care as being for those who are at the end of life without quantifying or elucidating any further. In the introduction to the release, the government widens this by stating their commitment is for high quality care *'for everyone approaching the end of life'* (Department of Health, 2016, p.7). This rhetoric might confuse not only medical professionals but the general population as it could be that, albeit in a more philosophical rather than biological or medical sense, everyone is approaching the end of their life. End-of-life care is seen as being inextricably linked to definitions and understandings of palliative care by the UK government. NHS England use both terms simultaneously, for example when discussing people with life-limiting illness and their care:

'They are likely to have needs that are often referred to as palliative or end-of-life care, especially as they approach the last year(s) of their lives' (NHS England, 2016, p.5)

It is worth noting the use of both terms – palliative and end-of-life care - as interchangeable, and the use of the bracketed 's' which would suggest the NHS sees palliative care as potentially being delivered for longer than 12 months. While this may sound plausible, it would appear there is still a time frame used when identifying people who are at the end of their life. Walshe *et al.*'s (2016) qualitative study provides an example here. They considered the use of volunteers in end-of-life care and defined the end of life as the last 12 months of expected life for their participants, the same time criterion also used by Holdsworth and King (2011) in their exploratory study with patients into preferences at end of life. This timeframe of 12 months accords with that of the National Institute for Clinical Excellence (NICE, 2017a), and the General Medical Council who state that *'patients are approaching the end of life when they are likely to die within the next 12 months'* (GMC, 2010, p.86).

The interchangeability of the terms palliative and end of life appear to be used not just in governmental documents, but also within research itself. McDermott *et al.*'s (2006) systematic ethnographic analysis of research into the care of cancer patients at the end of life offered no real definitions of the terminologies. Their research then appeared to use palliative care when identifying the care professionals, and end-of-life care when identifying the care being delivered; a linguistic style which can also be seen in other studies (Holdsworth and King, 2011). Indeed, Izumi *et al.* (2012) acknowledged the interchangeability of end-of-life care, terminal care, hospice care and palliative care. They argued that there is still no exact definition of end of life, and what is constituted as end of life is usually a timeframe agreed in policy or administrative guidelines, as evidenced here. Indeed, Izumi *et al.* (2012) viewed end of life as *'a discreet time period when a person is aware of the end of life, not a medically determined period of time before death'* (Izumi *et al.*, 2012, p.616). This concurs with Jaarsma *et al.*'s (2009) report from a workshop involving professionals specialising in care for patients with heart failure. They used the definition that end-of-life care *"may begin as soon as an irreversible illness is diagnosed"* (Jaarsma *et al.*, 2009: p434). This view is also supported by Murray *et al.* (2017); they argued that there is considerable evidence for palliative care to be delivered much earlier to patients.

In summary, recent literature and research evidence suggests there remains no consensus of opinion on the definitions of the terminologies around care for people who are dying. It would appear that palliative care is an overall term for all care of people who are entering the final

stages of life due to a life-limiting illness or condition. What those stages are, and when they are anticipated or expected is still vague and poorly defined. However, dying can be perceived as the point where curative treatment is deemed to be futile, irrespective of timeframes, and when palliative care may begin. Hospice care is an element of that palliative care option which is increasingly seen as a specialised form of palliation: holistic, homely and a combination of a philosophical approach and a physical place of care. End-of-life care, however, is seen by others as a specific period of time, often as the expected last six months or year of life. The literature suggests that general definitions are considered neither appropriate nor useful due to the belief that every person assesses their situation and palliative/end-of-life care needs differently, particularly in connection with the subjective term of quality of life.

What is most insightful is that, regardless of official definitions of any kind, there are unwritten meanings within society which are perpetuated by those working within or utilising the provision, for example, the strong link between the care that hospices deliver and the physical space where it is perceived to be delivered. The connection to place has not been explored as much in research as a means of defining care and is discussed further in Chapter Four.

It is of interest to consider how the various constructs for defining hospice care discussed here resonate with patients with life-limiting conditions. I discuss these different perspectives in the next section, firstly looking at the importance of patients with life-limiting conditions in research, before focusing on the wider population.

3.2 The Importance of the Dying Patient in Research

Patient perspectives can illuminate various aspects of their experiences and challenge assumptions held by professionals about a patient's understanding and their situation. Therefore, patient views are becoming increasingly important in research and practice, not only to inform on what is effective, but also to offer clarification on outcomes from service delivery and help to ensure services are truly person-centred (Braun and Clark, 2019).

There have been numerous studies with chronically and terminally ill patients (Bailey *et al.*, 2016, Osborne *et al.*, 2014, Ohlen *et al.*, 2016, Romo *et al.*, 2016, Sampson, *et al.*, 2014). It is

imperative that these perspectives continue to be heard in order to influence our understanding and practice within care provision for patients at the end of life. This then enables new insight and perspectives to be considered when planning and delivering care. As mentioned earlier, this should include patients with non-malignant conditions as well as cancer. Often studies focus on one specific group of patients, such as those with a particular health condition, or studies may be linked to a particular characteristic such as socio-economic status, ethnicity or gender. In this section, I consider how this patient perspective has been included in research, including specific groups of patients from different social, cultural and health backgrounds. I start with a brief consideration of research investigating patients' self-awareness of dying.

3.2.1 The Awareness and Knowledge of Patients at End of Life

The awareness patients have of their condition and prognosis are key factors which can impact on a patient's perception of the care they may need now, and in the future. There needs to be a recognition of what information is given to patients about their conditions, but also such things as the assumptions that are made about what is known, what should be known, or is wanted to be known, and how patients may cope with that knowledge. That continuum ranges from an open awareness of both the dying person and the medical professional or caregiver where they share that knowledge openly, to a closed awareness where the dying person is not aware of their prognosis and the other person is aware of that lack of knowledge (Glaser and Strauss, 1966).

In modern medicine it could be stated that practice is geared towards an open awareness with practitioners being as open as possible with patients. Indeed, there is a moral and ethical obligation for practitioners to ensure their patients have all the information and knowledge about their situation (General Medical Council, 2019). However, it is important to remember that, for some people, their coping mechanism may be to not want to know details about their condition or prognosis (Richards *et al.*, 2013). For others, it may be helpful to have a state of mutual pretence awareness as categorised by Glaser and Strauss (1966) whereby both sides are aware of each other's knowledge, but do not openly discuss it. This state could be possible where there is a reluctance to use specific terminology around death and dying,

the stigma of labelling a person as dying or of potentially becoming a hospice patient.

It is not always the case then that people are aware that they are dying, as Richards *et al.* (2013) identified in their qualitative study. They found in their interviews with 15 patients in the UK that many older people who were receiving palliative care were not as aware of their condition and prognosis as expected by the professionals delivering their care. This was especially the case for those over 85 years of age and goes against the generally accepted person-centred practice and wider societal view that people should be openly aware of their health conditions and have autonomy over their lives and decisions (Genuis, 2017). Awareness can be linked to whether a patient actually wants to be informed, but also whether the patient has been given enough appropriate and relevant information about their condition, prognosis, and options for care. Knowledge, or lack of it, can play a crucial part in the decisions made by professionals and patients at end of life, and clearly therefore how much information is given and understood is an area that needs investigation.

Another UK-based study conducted by Nagington *et al.* (2016) interviewed carers and patients with palliative care needs who were supported by district nurses. They found that knowledge of the dying process in carers and patients was limited, and that opportunities for patients to improve their knowledge of palliative care, such as through literature or from professionals, were also limited. They acknowledged that patients only became knowledgeable about potential care options when a nurse would actively offer that specific care, and so availability and access were heavily dependent on the healthcare professional. Solutions that Nagington and colleagues (2016) recommended included the empowerment of patients to enable their co-production of information leaflets on care options and establishing patient networking opportunities to learn from others about palliative care.

While these solutions may help to address the gap in knowledge and use of palliative care in that context, it would not necessarily be transferable to the general population. Also, the knowledge of the patients would be limited to their own experiences and, therefore, could lead key care provisions that other patients may find beneficial to be missed. It seems that there is a need for research to consider how this improvement of knowledge can be achieved for a wider demographic, going beyond current patients and healthcare professionals, which is discussed next.

3.3 Researching Different Perspectives within Populations

It is important to consider how the wider population perceive end-of-life care and those institutions which provide it, such as hospices. There has been limited research investigating the general public's views on hospice care specifically, and on palliative care more generally. Most studies considered in this section were conducted in the USA, but have comparative use for this research, as they are focusing on knowledge of hospice care provision, and people's understanding of what that means. There is a paucity of research from Europe and the UK where care is markedly different, and there is no comparable research which has asked the wider public about their perceptions of hospice care generally.

Research that has investigated how much knowledge people have around end of life and hospice care has tended to focus on what is, or is not known, rather than offering any theoretical reasoning to explain the level of knowledge. A study undertaken in the US by Cagle *et al.* (2017) focused on perceptions of hospice care amongst 123 US citizens through the use of a telephone questionnaire which comprised closed questions in the form of 23 true or false statements. While this did not allow for any qualitative data to be captured, it did give some important results. They found that over 80% of participants had heard of the term hospice, but that there were misperceptions around eligibility and access. The results indicated that a higher level of knowledge of hospice care was associated with a greater preference for hospice care. They also found that ethnic minorities were less likely to have knowledge of hospice care. Cagle *et al.* (2017) concluded by stating that common myths around hospice care need to be revised, in order to increase access and equity of the use of hospice care, and to improve attitudes towards hospice care. These conclusions reiterate the need for the wider population to be included in research to better understand and improve perceptions of hospice care.

Researching palliative care knowledge of the general public in the US was undertaken by Kozlov *et al.* in 2018, again though a simple closed questionnaire of 13 true or false statements answered by 301 participants. They concluded that most laypeople were unaware or misinformed about palliative care. While this gave a good insight into the lack of understanding and knowledge of the general public, the use of open-ended questions could have helped to get more detail about participant's perspectives. One key finding from Kozlov

et al.'s research was that nearly 50% had not heard of palliative care. The researchers did acknowledge that there may have been some confusion in participants between hospice and palliative care when answering the questions, and it needs to be acknowledged that the terminology may have different meanings within US culture as compared to UK and Europe. Kozlov *et al.* (2018) hypothesised that if people believe misinformation about what palliative or hospice care is, this can potentially be a barrier to accessing care, for example, that care is only for the last six months of expected life. Kovlov *et al.* (2018) stated that for palliative care to be the most effective it needs to be accessed much earlier in a patient's trajectory. If patients are delaying intervention, this will impact on its value for the patient.

A similar project researching the understanding of hospice and palliative care with 800 residents of New York was published in 2018 by Shalev *et al.* They based their hypothesis on the assumption that there are negative misperceptions and low knowledge levels within the general population. Unlike the other earlier studies in the US, they posed only three questions, but these were open-ended and focused on defining hospice care, defining palliative care, and whether they would recommend it to people they knew. Their results found that, while people may have heard of the different labels of care, they were unaware of the key components of that care and concluded that this could impact on access and use of care provision.

One recent study from outside the US did evidence a lack of knowledge among health and non-health care professionals. Dixe *et al.*'s (2020) online survey with Portuguese professionals demonstrated significant gaps in understanding. Myths such as palliative care being only for cancer patients, palliation only being used when everything else had been tried, and that care was only delivered in healthcare settings, were evidenced findings from the data and led the researchers to conclude that knowledge needed to be improved among not only the general population, but also among professionals.

None of these studies commented on whether they checked participants' prior involvement or knowledge. For example, participants may have been healthcare professionals or had experience of a family member who had received hospice care, or indeed may have been currently receiving care themselves.

The limitations in all these studies are clear, not just because they are focused on the Western world, primarily the US, but also because, due to their methodologies, they were not able to consider in depth the perspectives of their respective populations, merely providing evidence of a lack of knowledge. Asking closed questions in a questionnaire where there are only two possible responses or asking only three open-ended will limit the amount of data and insight into the perceptions of the public. However, different perspectives from the wider population, and arguably a wider population worldwide, are necessary to gain a clearer understanding of how hospice care is understood, perceived, and utilised.

3.3.1 Public Health and Care at the End of Life

The reasoning behind research into public perceptions and understanding around any care for people with terminal illness may be due to increasing importance within national policy and practice, as demonstrated in the previous chapter. End-of-life care is clearly a part of care more generally, and therefore has been considered when adopting local and national policy and guidance within the UK. Indeed, some of the aims of general health and social care policy is highly relevant for end-of-life care, for example the focus on integration of care, personalised care, and supporting families and carers (Sleeman *et al.*, 2019). Having said that, end-of-life care is often not given priority or even explicitly mentioned in general health and social care policy. After a review of current general health and social care policies, Sleeman *et al.* (2019) concluded that if palliative care priorities could be more aligned with general health care priorities this could help to reduce inequities in access to care at the end of life. Even though there are dedicated policies and guidance on end-of-life care, such as NICE *Clinical Guidelines for Care at End of Life* (2019, the *One Chance to Get it Right* government guidance (Department of Health, 2014), and NICE Quality Standard For End of Life Care for Adults (NICE, 2017b), it seems that in order to improve quality of service, reduce costs and increase public choice, end-of-life care needs to be incorporated much more into generalist health and social care guidance and literature (Hunter and Orlovic, 2018).

The development of specialist palliative care services, hospice provision, and advancements in prolonging life and symptom control, together with the growing importance of autonomy and individualisation of patient care has therefore created demand and opportunities for

research and piloting within community initiatives. One area this could be seen in would be the development of a more community-based model of care, moving care out of hospitals and clinical settings. This isn't in isolation from the specialist and generalist care provided, but more working in partnership and integrating a more holistic approach to providing care and support at end of life (Abel *et al.*, 2018). This integrative model would include local and national public sector and third sector organisations supporting communities and liaising with specialised and general care services to meet the needs of their local populations. This is evidenced in the *Public Health England* report in 2016, the IPPR briefing paper in 2018 (Hunter and Orlovic, 2018) and the *Ambitions Framework*, recently updated for 2021-2026 (National Palliative and End of Life Care Partnership, 2021). A government-funded national audit of care at end of life is still ongoing at the time of writing this thesis and recommends better integration of services across both the national and localised settings (HQIP, 2020).

Kellehear (2005) developed a model around compassionate communities to attempt to reduce the taboo and stigma around death and dying, to de-medicalise care of the dying, and to bring dying back into the normality of everyday life. This has been launched in various countries worldwide including the UK. Indeed, community models of care have seen growing development in the UK, with several initiatives, both national and local being explored and instigated. Some of these have focused on raising awareness such as Dying Matters, the Death Café Movement, and 'Let's Talk About it', while other schemes have considered more practical support and care for people using Kellehear's original ideas to develop compassionate communities and implementing the Dying Well Community Charter, or adaptations such as Sallnow *et al.*'s (2016) 'Compassionate Neighbours' programme. This is also alongside other regionalised and local initiatives such as arranging events, for example You Only Die Once (YODO) in Birmingham and the Departure Lounge in London. These are all examples of how the Government's *Ambitions Framework* has been put into practice in relation to the development, integration and empowerment of local communities to support their population who are identified as at end of life. It also highlights how important it is not only to acknowledge and understand perceptions of death and dying, but also to challenge and expand those perceptions in order to generate change and improvement in care provision, including not only that provided by general health providers, and the community, but specialist services such as hospices.

This chapter has demonstrated the current issues within hospice care research, from the foundations of the terminology used in care for people who are dying, to the need for inclusion not only of the patient voice within research, but arguably the need for a wider societal inclusion in research into the perceptions of care for people at this stage of life. The theories of the therapeutic landscape of hospice care, and the stigmatisation and labelling of dying, hospice care and being a hospice patient are useful to draw upon when considering those perceptions and views on hospice care. These are considered in the next chapter.

4. Review of the Theoretical Framework

The previous chapter reviewed some of the key literature on defining care for patients with terminal illness and looked at how patients and the wider population have been included in research focusing on end of life and hospice care provision. In this chapter I introduce the theoretical framework of this research and consider the key literature. Looking at the issue through a social constructionist lens, it is important to understand people's perceptions of care provision as this would be their view of the reality of care. As demonstrated in the previous chapter, people's attitudes and perceptions shape their understanding and possible behaviour. Therefore, it is necessary to review the theoretical aspects of people's understanding of hospice care, and how they perceive a dying person.

Studies researching health and health care often do not fit comfortably within health studies, sociology, or human geography, as the impact of health and illness often crosses several specialties, with research and strategies rarely residing purely in one discipline alone (Tritter, 2013). Therefore, I draw here on theories from two different disciplinary areas: geography and sociology. A conceptual map demonstrating the theoretical background to this research is shown in Appendix 1, which also demonstrates how some of the related theories discussed inter-relate to these two main theoretical areas of geography and sociology. I now explain my reasoning for each of these fields in turn.

The geographical aspect of hospice care is important for this research as there is a clear physicality: the physical presence of hospices within the UK, and the physicality of the self: our bodies as a living and dying form. Adopting a case study design for the research is well suited to geographical research as often a geographical area, or a selection of areas, is chosen as the specific case, particularly when considering inequity of service (Skinner *et al.,* 2018; Thornham and Parry, 2014; Gatrell and Wood, 2012). Using geographical theory and case study design is also highly relevant in geographical studies as people's identities are inextricably linked to their environment. Leach (2007) argued that the meaning people attach to a place, helps to affirm their own identity, as well as the identity of the place itself, for example the connection of a hospice patient to a hospice setting. Therefore, I outline in this chapter the growing area of research in health geography that is the landscape of care, and the related concepts of topophilia and topophobia.

The importance of sociology to this research is that, due to the deeply human and emotional aspects of death and dying, social theories around interaction and identity of self and others are key components of death and dying research, particularly in relation to the labelling of someone as dying. How people perceive their health and care needs, and other people's health and care needs impacts on their understanding, and how they interact with each other. This is highly relevant when undertaking qualitative research which is focusing on people's socially constructed view of their world and their lives within it.

There now follows a review of the literature from both these theoretical frameworks in relation to the field of hospice care research. Firstly, I consider the relevance of the theory of therapeutic landscapes to death and dying research, including the concepts of a landscape of care, and the understanding of topophilia and topophobia. Secondly, I draw on Goffman's theory of stigma, which, as a sociological concept has had significant impact across a wide range of research since its formation. I outline this in order to consider how the dying person may be stigmatised, perceive stigmatism themselves, and the association with othering and labelling of hospice care and being a hospice patient.

4.1 Therapeutic Landscapes

Health geography is a large field of research within human geography which covers diverse topics. It brings together the discipline of geography, with the substantive area of health and social care. Health geography is centred around understanding health and illness; the services and resources which are connected to health, and how both are influenced by place. It arose from the field of medical geography, with the defining difference being the alignment of health to the concept of space, rather than a specific illness, or disease. Health geography became established in the 1990s through focusing on the cultural, environmental and social aspects of health (Kearns and Gesler, 1998). It is also linked with other disciplines including epidemiology and sociology (Cummins *et al.*, 2007). Kearns and Moon (2002) helpfully divide the diverse health geography field into three distinctive areas: critical health geography, theory, and place. I intend to focus on that concept of place, because of the connections of hospice care to that physical setting of a hospice building as a place of care. Place is defined as a space which has meaning attached to it, and therefore the focus is on a more emotional and influential landscape (Kearns and Gesler, 1998).

Crang (1998) discussed the concept that a landscape can have multiple meanings to different people, using the example of a country house having different representations for the people living there, the people visiting, how it is viewed in art etc. Applying this to hospice care, it might be extrapolated that hospices, too, are places that are viewed and understood differently by patients, volunteers, carers, staff, visitors, and the wider general public. This would include those outside of hospice provision who have never actually been to the location, but have strong attitudes and beliefs about the building, what it signifies, and the care that is delivered within the place. These multiple meanings held by various stakeholders need to be investigated in order to unpack a more holistic understanding of this landscape of care.

In fitting with a social constructionist lens, Gesler (1992) has described landscapes as being fluid with multiple realities, that is, coming from people's understandings and perceptions as well as the physical world (Curtis and Rees-Jones, 1998). This fluid environment was defined as a therapeutic landscape by Gesler and included cultural and social beliefs about care delivery and distribution (Milligan and Wiles, 2010), as well as the relationships people can

have with care settings (Baxter and Fenton, 2016). The definition of a therapeutic landscape then is markedly similar to the holistic definition of hospice care:

'Therapeutic landscapes are places that have achieved lasting reputations for providing physical, mental, and spiritual healing' (Kearns and Gesler, 1998, p.8)

For Gesler (1992) the healing was seen as much more than a physical healing in the biomedical sense, but as encompassing the healing that can occur socially, psychologically and spiritually. The connection to hospice care and the total pain concept of Cicely Saunders is clear. It suggests that while patients may not be healed in the traditional biomedical sense in a hospice, they do experience forms of healing for their psychological, emotional and spiritual health, as well as the relief of physical symptoms associated with their medical condition and the dying process.

The theory of therapeutic landscapes has developed since its first presentation in 1992, to respond to some of the critiques of Gesler's original concept in which the terminology was considered restrictive, with medical connotations creating confusion as to what actually was meant by therapeutic, and the rigidity of the term landscape. Some researchers broadened out landscapes to include those that are imaginary or perceived (Lengen, 2015), as not all landscapes need to be physically experienced to have an impact on someone. These landscapes could come from a historical connection or just a perceived understanding of a place, possibly from media representation or the influence of peers. Others such as Warner *et al.* (2013) and Nagib and Williams (2018) believed the term had been focused more on exceptional settings such as those Gesler (1992) first considered, including natural springs and religious sites of pilgrimage, and so they shifted the focus onto the ordinary, everyday world, such as people's homes.

Of course, the concept of a place having a positive therapeutic affect can also be challenged due its subjectivity: a setting may be pleasurable for one person, but deeply traumatic for another. This concept of multiple emotional responses to a place was considered earlier by Bacherlard (1958) in his seminal work on poetic imagination. He discussed how a house may have parts which are both loved and feared, within the same building. The linking of a place with an emotion is credited to Tuan (1974) who originated the term topophilia. He understood this love of place from the relationships people form with their environment and

examined positive perceptions of the environment in relation to attitudes and values. He argued that culture influenced the positive relationships between people and places, including their understanding of its history, and the symbolism they may attach to a place. Tuan (1977) later combined the concepts of topophilia and topophobia in his discourse on space and place, where he acknowledged, like Bachelard before him, that a place can be both loved and hated by different people because of their own individual culture, or experience and relationship with that place. The idea of an individual, or indeed a population, loving and/or fearing a place simultaneously can be seen to have deep significance for hospice care provision, and people's understanding and attachment to hospices. In the next section I discuss how these ideas have been applied in research on community settings.

4.1.1 Perceptions of Community Resources in a Therapeutic Landscape

The therapeutic landscape has been applied to various environments including hospitals and other community buildings. Skinner *et al.'s* (2018) US-based study of a hospital setting involved 35 interviews with local residents and community members. They argued that hospitals could benefit from working with local communities to better understand how their space is perceived when they are planning care, and to enable the buildings to become more included within their local communities. A scoping study by Thornham and Parry (2014) considered the use and symbolism of community buildings and how they have been influenced by the locality and continue to impact on that locality. Through three interviews, six focus groups and observations of three different community centres, they found that the original purposes of buildings, often initially shaped by local and national authority and policy, changed over time through the development and adaptation by community use to meet changing community need. This often results in a change to the original planned purpose of the building. To apply this finding to a hospice setting, the original design and plan for the hospice building would have been to create a space away from hospital and home as a place for people to die, as discussed in Chapter Two. This original design is of course now markedly different from the main purpose of modern hospices, certainly within the UK, as the focus goes beyond providing in-patient care at end of life, to a longer period of wider support, with a wider range of provision within the hospice itself, and also in the local community setting

and in people's homes. Thornham and Parry (2014) argued that it is difficult for a building to re-create a new, different identity through its current and future use, describing the possibility of a symbolic (possible mis-) representation of the building and its role and function within the community. Clearly this can be seen within the hospice movement in the UK where the symbolism of a hospice as a place to die still lingers within societal understanding. More recent research by Gibbeson (2020) concurred with this difficulty in changing the symbolic understanding of a place. She particularly noted this in relation to her research into physical sites of mental asylums, and their associated stigmas:

'The longevity in a stigma persisting results from that stigma becoming a myth or urban legend which continues to be written and rewritten in the history of a site until it becomes part of the identity of that place' (Gibbeson, 2020, p.3)

Gibbeson's statement can easily be seen to relate to hospices. During the 50 years of the Modern Hospice Movement there has been a persistence of the myths that hospices are places for people to go to die, and that has indeed become the identity of hospice buildings. In their research Thornham and Parry chose to only involve participants who were directly connected to their research sites, and not include the perspectives of other local people who may use the building in the future (or indeed previous users). Key data could be missing to evidence important possible reasons why some people do not engage with their community building. Similarly, Gibbeson's research may be limited as it focused solely on the understanding of the people connected to the research sites, rather than the wider communities who may have different perspectives. Any research into hospice care, and the purposes of hospices, needs to be undertaken beyond the normal scope of patients, hospice staff and family members, so as to include those who may use the services in the future, or who are choosing not to engage with its current provision.

As within any society, the local community that has been studied here isn't just a community that has a hospice, but a community that has a relational structure for its resources. That relational structure is taken from the structuration theory of Giddens which stated that availability and access to health services such as hospice care within a specific area, in this research the geographical area defined as Milton Keynes, is dependent on the relationship between the structure, i.e. the hospice itself, and the community it serves (Giddens, 1991).

This means that involving communities more through raising awareness and understanding of hospice care can help to shape and direct that care in the future. While this study is considering the perspectives of communities within a specified geographic location, the data has been very much focused on the individual perceptions of participants, and as such theories such as structuration have not been considered in great detail for this research, but structuration theory does suggest however that the hospice isn't just a passive place providing end-of-life care, but is an active participant in social change (Tural, 2019) and therefore needs to be involved in and be in control of its part in social change, specifically changing the perceptions and understanding of hospice care provision.

Seeing places connected to health, such as hospice settings, as a part of our local communities is important. Gesler and Kearns (2002, p.37) referred to *'cultural geographers of health'* where health research is placed within local cultures, societies and communities. That research needs to include hospices, and in the next section I outline where such theories have been used within hospice care research.

4.1.2 Therapeutic Landscapes within Hospice Care Research

Therapeutic relationships have developed from those original ideas discussed earlier into a more relational concept. Conradson (2005) concluded in his qualitative research with patients with physical impairments at a respite centre, that the therapeutic value of a place was much more relational; affected by the interactions, activities and experiences of the patients, rather than just being a product of the physical environment itself. For a hospice, that therapeutic benefit and value may vary between inpatients, day patients, patients receiving care at home, health professionals, visitors, and those who have no actual connection to hospice care provision. Each group will have different relationships and emotional attachments to that care and the place of care. It could be easy to assume a hospice is understood in this positive therapeutic way; however, without research into that relationship between different groups of the population, it should not be assumed. When considering the relational impact of a place on a population, it is easy to see how that place could have multiple meanings and values dependent on those interactions. One person may have a positive therapeutic response, but for another it could be deeply traumatic.

Research around hospice care provision has not often considered it from a health geography perspective, apart from occasionally when the design, architecture, and planning in relation to where hospice care is sited have been considered, or in relation to the physical access to hospices for a local or national population (Chukwusa *et al.*, 2020; Gattrell and Wood, 2012; Moore *et al.*, 2013; Verderber, 2014). There has been some discussion around seeing landscapes beyond the spatial location (Milligan and Wiles, 2010). This means seeing the hospice more abstractly, including not just the actual delivery of the care and the physical building, but also, taking Conradson's point from the previous section, the relationships and interaction between staff, patients and their environments. There is also the imagined setting, how it is perceived by those not connected to its care provision. These can all play a significant part in how people may understand and respond to hospice care. They can also influence people's emotional attachment, and also detachment, from hospice care and the providers of that care environment, whether that be within the hospice itself, in the patient's home, outreach services, or within the imagined mind of the general public.

Seeing landscapes beyond the spatial location was neglected by Gatrell and Wood (2012), who focused purely on the physical distance for patients accessing hospice care provision within a rural locality in their quantitative study. Their findings related to how rural locations impacted on physical access to provision; they did not consider other geographical factors that may influence the use of a service, including access to public transport, cost of transport, and also people's understanding of its therapeutic value influencing a decision to attend. Moore *et al.* (2013) conducted research which looked at how patients perceived their hospice care. In their phenomenological qualitative study, they interviewed 11 patients using a specialist hospice service and found that the patients were very focused on the place of care: that space where they received support. They concluded that while hospices may focus on their philosophy and ethos of care, this reduces the importance of the place of care which in contrast is often the patient's focus. Their solution was that hospices should instead be *'co-constructed between philosophy and place'* (Moore *et al.* 2013, p.151) to reduce the focus by patients on the physical location. It would have been interesting if they could have included patients who were not part of the hospice provision to ascertain any difference in perceptions.

Research addressing the geographical concepts of space and place within hospice care is limited. Most research focused on actual experiences of care settings, either current experiences or retrospectively (Rasmussen and Edvardson, 2007; McGann, 2011; Ohlen *et al.*, 2016; Waller, 2013) and neglected how a wider range of people perceive that care landscape, going beyond the users of that space. Rasmussen and Edvardson (2007) researched patient's perceptions within an inpatient hospice ward in Sweden but did not acknowledge if the hospice researched provided any care away from the residential setting. Zadeh *et al.* (2018) undertook a literature review focusing on the care environment for end-of-life and palliative care, which also appeared to only consider specific care settings such as hospital wards and hospices, that is, built environments for care, as opposed to hospice care within an informal setting such as a patient's home. They did conclude however, that the environment can affect the care delivered. McGann's (2011) discussion paper considered the spatial practices of hospice care within the home environment. This is particularly relevant in considering the drive towards people's preferences for dying at home. She acknowledged that, historically, death was not a consideration in hospital design, and that this had contributed to the development of the hospice as a separate place for death and dying, with a strong focus on hospice care being delivered physically at the hospice. This focus has not developed beyond the hospice setting to the home environment, despite most hospice care now being delivered outside of the actual hospice setting.

While the research discussed in this section gives valuable insights into the geographical aspects of hospice care, it has also highlighted a need to widen research to consider a range of experiences and perceptions on the care environment beyond patients and staff, as there is very limited representation from the wider communities around local hospice provision. When considering local communities and the hospices within them, social theory can help explain some of the perceptions held by patients, staff, volunteers, family and friends of patients, and the wider local communities around the physical setting. I discuss this in the next section in relation to the social theory of stigmatisation and labelling.

4.2 The Theory of Stigmatisation and Labelling

Stigmatisation is a theoretical concept first developed by Erving Goffman. His ideas focused on the concept that a person's attributes, such as having a mental or terminal illness, could be *'deeply discrediting'* (Goffman, 1963, p.13). Goffman acknowledged that these attributes could be a visible difference, for example, a physical disability or personal characteristic, or something that is hidden such as autism or a diagnosis of cancer. In his early work he used the examples of mental health conditions from his work in institutions. Goffman's use of the term abnormal within an institution specialising in mental health can easily be transposed into the abnormality of dying within a society or cultural setting. This would be in contrast to the normality of being alive and actively participating in the world, particularly with Westernised views of prolonging life and good health, and illness seen as failure (Hawley, 2017).

Goffman recognised that it was the types of social interaction (or inaction) that fuelled the labelling and stigmatisation of people who were considered different to the norm. Indeed, the stigma is experienced through this relationship difference, and social interaction between those society considers normal, and those seen as abnormal. The abnormality can carry certain labels connected to aspects of a person such as their gender, health or status. The theoretical understanding of stigma and labelling have, and continue to be, applied to many other circumstances where a person, or group of people, are different. In this study, I consider a population who are eligible to receive hospice care, that is, within their last year of expected life, a difference to the norm of living, a concept that I discuss later in this chapter. Firstly, I discuss the background and relevance of stigma and labelling for people who are dying, and then move onto these theories within a societal context.

4.2.1 The Use of Stigma on Death and Dying

Goffman's work has been widely used and adapted by other theorists and researchers since its first inception in the 1960s, including those working in health research (Eaton *et al.,* 2018; Heim *et al.,* 2018; Vally, 2019). Link and Phelan (2001) are key authors who have expanded the concept of stigma to death and dying. They posited that stigma was a form of identifying

differences in people, which could lead to a stereotyping of those differences and an othering between 'us' and 'them'. They concurred with Goffman that stigma can create a loss of status, and possible discrimination towards the stigmatised person or people, emphasising a negativity associated with that stigmatisation. This enacted stigma can be identified within death and dying when considering the attitudes of people, particularly in the Westernised world, towards death and people who are dying.

Stigma can come from within a person, as a result of their own perceptions or interactions with others. Goffman (1963) considered how a stigmatised person may view themselves, or their perceptions of how they think others view them. He acknowledged that whether it is a visible or hidden difference, the person will have an awareness of that difference, and may accept it, or have a desire to fit in with the norm as much as possible. This may be attempted by hiding their difference or by withdrawing away from society to form *'new relationships'* with people similar to themselves, or who understand them (Goffman, 1963, p.49). This can be seen in the day hospice setting, where hospice patients visit regularly to socialise together with a collective understanding, albeit unspoken, of sharing that label of dying. Hiding away because of an actual or felt difference to the rest of society is a concept researched by Cagle and Bunting (2017). Their research linked stigma with a patient's reluctance to admit and discuss their own condition and discomfort when experiencing pain. They found this was due to the patient's own perceptions of a potential reliance on medication, perceived attention seeking, or an admission of not being able to cope, that is, admitting to the presence and possible unmanageable nature of their pain.

Withdrawing from society was discussed in research by Willig and Wirth (2018) in their study of cancer patients at end of life. They observed that patients created a sense of othering or self-stigmatisation as they became more connected to the natural world, and withdrew, or disconnected from family and friends. Whether this could be classed as self-stigmatisation is debatable, as it may not necessarily be a negative response to the awareness of dying, but a reaction that felt positive for the patient. Willig and Wirth did acknowledge this concept needed wider recognition and possibly further research into how being labelled as dying can impact on a patient's social connections.

Not everyone does withdraw however, and Goffman theorised this when he noted the withdrawal or self-degradation of mental health patients. He stated that patients may create

themselves to be an exemplar of their condition in order to try and assimilate into society. He identified that people may use their difference to benefit themselves as an ambassador of a stigmatised category, or as Goffman puts it *'instead of leaning on their crutch, they get to play golf with it'* (Goffman, 1963, p.39). This can be seen within modern society in people who publicise their experience of dying through writing or film (I am Breathing, 2013; Levine, 2018). So, while they may be identifying themselves as different, this is used not to withdraw, but actually to be different while remaining within society, thereby not being a negative experience of difference, but something that can be a positive.

More recently, Brons (2015) focused on Hegel's [1807] influential text, the Master-Slave Dialectic, and the concept of othering in his analysis. He focused on how people identify themselves and others, as well as how they distance themselves from others. Brons acknowledged that this separation of self and other can be a neutral difference in contrast to the negativity of stigmatisation previously described. It is important therefore, when considering identifying difference, that for the person, it may not necessarily be considered negatively. However, being identified as 'dying' may create a form of stigmatisation, because it can be seen as distinct to 'living', and therefore abnormal. This difference between living and dying is important as it can be viewed as another form of labelling. It may also seem more abstract than other forms of labelling, as living and dying are not necessarily mutually exclusive even if they may be perceived as such by the person themselves, or within societies and communities. The next section considers the concept of labelling in relation to studies in death and dying.

4.2.2 The Labelling of Death and Dying

Labelling has been often connected with stigma, as Grattet (2011) explained in his paper where he stated that the labelling of a person can occur because of a deviance or difference which can then lead to the manifestation of stigmatisation. Grattet further acknowledged that while labelling developed primarily in fields of criminality in relation to deviancy, it also developed in medical fields in identifying people who were different to the norm, such as alcoholism or sexual dysfunction. It could therefore be applied to the labelling of people as living, i.e., healthy, and dying. Grattet al.so pointed out that this labelling does not necessarily

always have solely negative connotations as Brons discussed earlier. This can certainly be seen in how attributing a label, or rather a diagnosis to a person, can then enable that person to access support and treatment for that diagnosis. In the context of this study this would mean obtaining a label of dying, of being diagnosed with a terminal condition, which can then hypothetically enable access to hospice care.

Accepting a label of dying can be difficult for patients especially when they are still attempting to live what society would see as a normal life. Flaherty's (2018) ethnographic work with a terminally ill patient explored their perceived labels of living and dying. Flaherty noted an existential ambivalence, where the patient expressed her difficulties in coming to terms with dying while trying to live, and the emotional and psychological fluctuations this created. Flaherty found that accepting hospice care was not necessarily an acceptance of dying, but rather an acceptance of requiring medical care. However, this acceptance may be difficult when the public perceptions of palliative and hospice care are poor, often connected to misperceptions around death (Patel and Lyons, 2020).

The idea of dying, and therefore being attributed with the label of dying and of being abnormal, compared to the norm of living was considered by Ellis (2013) in her ethnographic study of families living with chronic illness. She considered how Western thought had isolated the experience of death, linking this with the concept of labelling. Ellis explained it using the rupture model, where death is seen as alien to the normality of living. She discussed how this ruptural thinking caused a loss of identity, similar to Goffman's concept of stigma, based on her qualitative interviews of people with cancer diagnoses. In her study, Ellis found that dying needed to be considered more as an everyday experience for humanity, rather than something disruptive and alien. Her participants viewed their dying as something which occurred alongside the mundane experiences of day-to-day living, rather than separate to it. Therefore, she concluded that dying people label themselves, as both living and dying simultaneously.

This conclusion was contradictory to Willig and Wirth's (2018) metasynthesis of 23 studies involving interviews with people who were dying. Willig and Wirth discussed the liminal space between life and death and found that there was a need for people who are at the end of life to remove themselves from the day-to-day experiences of living in order to '*gain access to a*

sense of fulfilment and joy' (Willig and Wirth, 2018, p.4). Furthermore, for some patients, there may be a need to distance the two labels of living and dying, possibly due to the negativity around the dying label, and its restrictions to their understanding of what life is and means to them, or because they are not yet ready to accept that label as who they are. This might be seen as redefining a different way of living, so they concluded dying was a different stage of life, a time to live differently, rather than, as in Ellis's (2013) conclusion, more an acceptance of dying, but continuing to live in the same way.

These labels are important then to consider particularly in relation to the patient perspectives, and how they perceive themselves: are they dying, living, or both? While there can be some positives in these forms of labelling as discussed, there is also the potential for suffering and distress. They may find it hard to manage this emotionally and psychologically, particularly within their own social circles, which can cause the withdrawal from society. However, how those societies view the stigma of death and dying may also have an influence on patients who are dying, which is discussed next.

4.2.3 Structural Stigma and Labelling of Death and Dying within Societies

So far, the focus of this section has been on the individual, however, the theory of stigma is strongly associated with how societies view difference. Link and Phelan (2001) picked up on this aspect as a criticism of Goffman's theory which they perceived was too focused on the individual. Hatzenbeuhler and Link (2014) developed the idea of structural stigma, defining it as:

'*Societal-level conditions, cultural norms, and institutional policies that constrain the opportunities, resources, and well-being of the stigmatised*'

(Hatzenbeuhler and Link: 2014, p.2)

Within some societies, death and dying are still seen as taboo topics, often avoided in conversation, different and deviant from the norm. Those societies therefore can create a stigmatisation of dying, death, and the care that is received when a person is dying (Bhatnager

and Joshi, 2013; Mosher and Danoff-Burg, 2007). Link and Hatzenbeuhler (2016) also addressed the concept that stigmatisation does not occur in isolation but can impact across people's realities within their communities. How a dying person is perceived by the wider community, whether that is family and friends, health professionals, or other members of the public they may come into contact with, is highly influential on how that person feels about themselves and how they may choose to live their life.

A change in identity caused by this distancing of society was highlighted in an ethnographic exploration by Hemer (2018). She noted in her research within local communities in Papua New Guinea that there were societal changes in behaviour and attitude between the dying person and their communities, affecting their care and relationships. As this concept of a social death occurs in many societies it can be expected that when a person, through a life-limiting condition, becomes aware of their own mortality, they may also become aware of their own possible social death, and the stigma and othering that may occur towards them. This could potentially create a fear or reluctance in patients to accept that possibility and that label of dying, because of their own awareness of the social death within their own communities. This can be an issue within the UK as well as other countries (Borgstrom, 2017). Whether a person chooses to withdraw, or society distances itself from a person, the result is what has become known as a social death, that is, dying to the living world around them and sensing a loss of personhood (Borgstrom, 2017; Kralova, 2015).

The concept of structural stigma was developed by exploring how policy can create, cause or ignore stigmatisation (Link and Hatzenbeuhler2016). As seen in Chapter Two, policies, legislation and official documentation are all heavily influential in the field of hospice care and can impact on how people perceive hospice care and their patients. This is evidenced in hospices, as the original concept for their creation was solely around providing a place where people could be cared for at the end of life, a place to die. This will have permeated the documentation at the time. However, that belief in hospices being a place to die has stayed with them throughout their growth and development. This has resulted in a societal stigma around hospice buildings as a place of death, and hospice care being for that final stage of actively dying. This can then create a strong association with the topophobia discussed earlier in this chapter.

This connection of structural stigma, and the stigma and topophobia of place is important when considering hospices, as there is certainly stigmatisation around hospices as places of care. Crang (1998) considered this stigmatisation and labelling as an unequal relationship of identities or characteristics which he stated is often connected to people's geographies, such as their connections to a hospice. Crang's definition then can be seen beyond the identity of the hospice as a care provider, to the concept of the structure and identity of the physical hospice space, where there can be an unequal relationship between the patients who use that hospice space, whether as inpatient or outpatient, and those who do not.

Garthwaite and Bambra (2017) undertook a significant research project of ethnographic observations and interviews within two diverse communities within the UK to discover people's perceptions of health inequalities. They noted in their work with the general public that there is a labelling behaviour and attached stigma around perceptions of place, as well as a difference within the person caused by their condition or prognosis of death. There is also a societal stigma around palliative care in general. One cause of this can be due to the negative perceptions that a patient accepting palliative care has given up or is a 'quitter' (Johnson-Shen and Wellman, 2019). Johnson-Shen and Wellman evidenced this in their quantitative study on the stereotypes and stigma associated with patient choice of palliative care. They found that not only was there a stigma present, but it may also be a barrier for accepting palliative care. While this was a US study, similar results for the stigmatising of care at end of life have been researched in other countries (Dixe *et al.,* 2020; Gupta and Givil, 2015; Harding, Nair and Ekstrand, 2019) suggesting this can be a worldwide phenomenon which may also be prevalent in the UK.

Of course, policies can also be influenced by the stigma that is already present within societies. Scambler (2009) discussed health-related stigma in his paper, which focused on the suggestion that there is a need to re-frame stigma to reduce its impact within health. He posited that a person's identity can link with their health condition and result in negative or discriminatory judgement from society which could then impact on social and health policy. Scambler suggests that, as Goffman (1963) noted, stigma is connected to the interactions between people, and therefore it can be reduced if the public and professionals are better informed, through policy and education, to remove the *'disabling environment'* or *'structural discrimination'* (Scambler, 2009, p.449).

Policy and procedure influence the practice of the workforce within health care, and structural stigma can be seen within those settings. Cherny's 2009 editorial comment on stigma within palliative care noted how, despite the knowledge of the quality of care given by palliative teams, some practitioners were still reluctant to refer patients to the service, because of the stigma of dying and how it would symbolise bad news for the patient. This demonstrated the structural stigma that is prevalent in health care systems around palliative and end-of-life care, and the stigma of the label of dying. Cherny hypothesised that providing a new label of 'supportive care' could help reduce the stigma and increase referral and usage of the service. This idea of rebranding care was supported by Murray (2017) who has promoted the use of the term 'anticipatory care' for services in Scotland as an alternative to palliative care.

It is interesting how the differences between the terminologies can affect how people perceive the same care, demonstrating the problems of use of language and definitions within end-of-life care service provision, as discussed in the previous chapter. Understanding how people understand and use these terminologies is clearly necessary in order to identify, acknowledge and address any stigma surrounding hospice care. This understanding needs to include not just staff, but patients, carers and the wider population, to create a more accepting and inclusive environment for hospice care to be delivered, even if that means a relabelling, or rebranding of that care.

4.3 Summary

This chapter commenced with a consideration of the theoretical framework that has been adopted for this research, where I have incorporated theories from health geography and sociology to illustrate the difficulties in understanding death and dying, hospice care, and becoming a hospice patient. The linking of stigma of place, structural stigma, as well as stigma of the person and their specific condition, indicates that stigmatisation is a very complex concept that can impact significantly on people's lives and their perceptions of themselves and others. Dying undoubtedly has a stigma attached to it, evidenced in Western societies and the research discussed here, and the strong emotional connections to place can

demonstrate both negative and positive perceptions of the labels of dying and being a hospice patient.

Therefore, these two theoretical concepts of therapeutic landscapes and stigma bring together people's perspectives about the positive and therapeutic nature of hospice care, alongside the perspectives about what it means to be dying and a hospice patient. Therapeutic landscapes can go beyond the physicality of the hospice, but also relate to the labelling and othering of the people using hospice care, and also into the imagined landscape of care that people perceive is delivered. This strongly links with the theories of stigmatisation, either as an individual, or as a society. This can be highly influential in terms of creating a negativity around the acceptance of dying that the label of hospice patient can instil, or indeed potentially a positivity about hospice care and becoming a hospice patient.

Stigma can influence policy and practice but equally policy and practice can influence stigma. These are fundamental considerations for care providers at end of life, and indicate the need, as Scambler noted, to reduce the disabling environment and discrimination within society.

Having reviewed the literature and outlined the theoretical framework, it is clear that further research looking deeper into perceptions of care for people with life limiting conditions needs to be undertaken. While death and dying are social processes, the practicalities of caring for those who are dying has become significantly medicalised as demonstrated in the development of hospices and palliative care discussed earlier. Therefore, there is a demonstrable need to understand and advance our societies in their role and purpose relating to caring for the dying, particularly in how that is manifested locally within communities. This study provides an insight into the perceived reality of a localised population. How that insight was achieved is explained in the next chapter where I discuss the practical aspects of this project and my methodological approach.

5. Methodological Approach

5.1Introduction:

This chapter discusses the methodological approach of this project in more detail, and how it was designed to address the following question:

How Does a Population Residing in a UK Town Perceive Hospice Care Provision?

Sections 2.2 and 2.3 of this thesis explain the setting of this research in detail, and the first section explains the philosophical foundations of this research, as this has influenced all aspects of the study. I then introduce the sources of data used and the methods used to collect that data, followed by an explanation of the analysis techniques and strategies employed. The chapter ends with a consideration of the validity of the study.

5.2 Theoretical Background

This section considers the background of the research, in relation to how it was designed and how the theoretical underpinnings influenced that design. I start by considering the initial design of the project which followed a case study methodology, before considering the philosophical approach to the research.

5.2.1 Case Study Design

This research initially was designed around a case study methodology due to the diverse range of data sources used, and the nature of it being a localised study focusing on one specific topic. Case study methodology can be difficult to define (Yin, 2014), but it is often seen as an in-depth study incorporating multiple sources of data concerned with a specific phenomenon (Yin, 2014). A widely accepted definition within qualitative research is that posited by Simon who stated a case study is '*an in-depth exploration from multiple perspectives of the complexity and uniqueness of a particular project, policy, institutions, programme or system in a 'real life' context*' (Simons, 2009, p.21). Adopting this approach meant therefore I was able to achieve a deeper investigation of the data.

However, during the analysis and writing up stages of the project, the research did not follow a pure case study process and therefore is not presented as such in this thesis. The research followed a more structured approach and formal presentation in line with the PhD requirements, in contrast to a pure case study format which are able to be presented in a less restrictive arrangement. However, case studies are important in research including research into health care generally and hospice care specifically, and the uses of case studies in looking in-depth into complex qualitative phenomena meant this design and grounding leant itself effectively to this doctoral project.

Using this as a background helped to shape this study and provide a framework for the processes involved in reviewing literature and collecting data. As case studies are holistic in their approach, I argue it is appropriate to conclude that the results from a study adopting a case study methodology that has researched the perceptions of a UK hospice, is of benefit to a wider audience. This would help to reduce these identified gaps both academically and professionally as practitioners and other stakeholders may *'read and use the case report for a better understanding and for practice improvements'* (Abma and Stake, 2014, p.1152). Others concur with the view that case studies can influence practice: Widdowson, for example, when considering case studies in psychotherapy research stated a belief that case studies offer a high external validity due to *'significant numbers of practitioners being able to extrapolate from the findings of the case study into their own research'* (Widdowson, 2011, p.27). Indeed, this multi-faceted case study approach is considered by Abma and Stake (2014) to be far more beneficial than other qualitative approaches, such as a series of interviews for example, as it enables a more complete and personal construction of the multiple perspectives and realities operating within that particular environment.

Case studies do not necessarily contain a pilot study element in their design; in fact, the pilot study for a larger project can be a case study in itself (Yin, 2014; Stake, 1998). This study did not have a pilot data collection stage due to the practical constraints of undertaking the research as part of a time-limited research project. Ethical approval was not secured until 18 months into the study period, and this did not allow time for any pilot study to be completed prior to the main data collection stage, even though this can be argued as a useful and necessary part of research (Malmqvist *et al.*, 2019).

This project can be described as an explanatory or instrumental study of the community perceptions of hospice care. Stake (1995) asserted that any phenomena or function of a case, cannot be studied until the case itself is understood. While Stake is referring to case in the context of a case study, I concurred with Stake and determined that this initial understanding of the case in question i.e., the Milton Keynes population, could be achieved by looking at the hospice's place within that local population. This study helps bridge the gap between researching specific functions or outcomes of hospice care, and its role and place within communities. This is achieved through researching one specific geographic area and its hospice in depth. The case study methodology therefore did influence the design of this research considerably; however, it was also influenced by the philosophical approach that was adopted, and this is described next.

5.2.2 Philosophical Approach to the Research

Hospice care is a deeply intimate and personal experience for those involved in delivering, receiving and managing that service. It is rooted in human experience and therefore requires an approach in research which considers the complex and multiple realities of those involved. In order to enable a greater understanding of the different perspectives and experiences of participants and how these affected their own understandings of hospice care and how it is defined, I adopted a social constructionist approach. Social constructionism influenced my epistemological standpoint, as this perspective is concerned with how knowledge is understood and created by individuals within their societies (Berger and Luckman, 2011). It is also how people use their experience, interactions and language to construct their own reality (Burr and Dick, 2017), which for this research relates to people's perceptions of hospice care. There is a strong focus on language and definitions in this research and how those definitions have shaped people's understanding of hospice care. It could be argued that there has to be an element of realism when studying hospice care, as hospices do, in reality, provide specific forms of care and support, and there have been studies which have adopted this standpoint. However, as this study is focusing on what people 'perceive' hospice care is, rather than researching what is actually provided locally, I argue that the socially constructed reality needs to be the primary philosophical stance for this project.

Taking a constructionist perspective means this research acknowledged that there are multiple knowledges, realities, or truths, which are dependent on conditions such as people's knowledge and experiences, as well as time and cultural location (Stainton-Rogers, 2006). This theoretical standpoint concurs with the thoughts of Berger and Luckmann (2011, p.83) who posited that objects could undergo *'objectivation'* whereby the object takes on a meaning based on the perceived purpose of that object in a particular context and time. The object can be, for example, a hospice building, or more abstractly, the care provided by the hospice. This can link in with a person's emotional attachment to that object and create an epistemological paradigm of the creation of knowledge through that person's experience, whether directly or indirectly, using their emotional responses at that time. Berger and Luckmann (2011) consider that identifying the reality of everyday life is only possible because people construct their realities from such objects. This influenced how I approached and analysed the data, as I was aware these were people's perceptions of the reality of hospice care and therefore, to me, this was their truth around what hospice care was, irrespective of what care was provided by the local hospice. I will now expand on the sources of data used in this research that informed those perspectives.

5.3 Sources of Data

As noted in the thesis introduction, this project is a qualitative study of representatives of the population of Milton Keynes and their understanding of hospice care. To gather in-depth data about hospice care locally, and to answer the question of how local communities may define and understand the hospice role, multiple sources of data were identified from within the local population.

Firstly, a variety of documents were collated as data relating to the history and background of the hospice, the locale and its population, and these were used in Chapter Two to describe the background to this study. Documents can be a valuable source of data, and I decided to include them as they can provide significant amounts of knowledge, particularly on the historic and background to a study site, participants, social, cultural and political setting of the research. While there is always the potential for bias, particularly from the author, the purpose or indeed who funded the publication, they were essential for this study in order that

an in-depth understanding could be reached as to the local and national ideology, political, social and economic stage.

As the research addresses how people living and/or working in Milton Keynes perceive their hospice care provision locally, it was essential to ensure many of those local perceptions were included, considering the constraints of time on myself as sole researcher. For this research, it was important for this research to include the perspectives of people who were dying, and those people working within the local communities who had the potential to refer people into hospice care. These two categories of patients and health care professionals are often the foci of research into palliative and hospice care. However, I also wanted to ensure the wider population were included in this research, who may or may not have some knowledge or experience of hospice care provision. This perspective is less visible in hospice research. The approach for this study therefore resulted in three groupings of participants: patients, professionals, and the wider general population. No other study of hospice care could be identified which included this broader general public demographic alongside identified patients and professionals from one local area. There now follows more detail about each of these data sources, and profiles of the interview and focus group participants can be seen in Appendix 2.

5.3.1 Patients at End of Life

To research understandings of hospice care, a key population to include was those who were eligible for that provision, that is, people with life-limiting conditions. It was important to ensure this encompassed not only hospice patients, but also patients who were not currently accessing hospice care. No other research could be found that included patients at end of life who were not known to the local hospice, alongside current hospice patients and professionals. Most research undertaken with patients has been with those who were currently accessing or who had previously accessed the specific care or treatment being researched. As hospice care in the UK is primarily a charity-run service and not part of the NHS, there is a significant shortfall between those eligible to receive hospice care and those who are actually known to hospices. I strongly believe that this perspective of patients not accessing hospice care needs to be included in a greater number of studies, especially when

considering the debate on the current inequalities of palliative care and the need to widen access, as highlighted in Chapter Two. I was therefore sure I needed to ensure non-hospice patients were recruited as part of the patient data collection.

5.3.1.2. Recruitment

To identify potential participants, patients were referred to the study by their health care team only if they were in their last year of expected life. This is a common identifier within palliative care which is embedded in the Gold Standards Framework Prognostic Indicator Guidance (Thomas *et al.*, 2016). This is often used by professionals when assessing need; it is referred to as the 'surprise' question, that is, would a professional be surprised if the patient died within 12 months (Downar *et al.*, 2017). Therefore, I felt it was appropriate to use this criterion for recruitment for this study. I used clinical gatekeepers from the hospice and local health service who were asked to identify participants using their expertise and knowledge of patients. This included not only knowledge of their prognosis, but also their mental and physical health to reduce risks of harm if involved in the research. I also emphasised to the gatekeepers that a range of terminal conditions would be required, and so, while most had a cancer diagnosis, I also included a patient with a neurological condition, and two with respiratory conditions. Once identified, patients were given more information (see Appendix 3) and a consent form (Appendix 4), and I was supplied with their contact details to discuss the research further and possible involvement if they decided to proceed.

Patient Sample

Recruitment was ongoing throughout the data collection phase and resulted in the following patients participating in interviews. Pseudonyms were created to protect the patient's confidentiality and anonymity.

Patient Pseudonym	Diagnosis	Offered Hospice Care	Offer Accepted
Alan (Male, 75)	Heart Failure	No	-
Barbara (Female, 57)	Cancer	Yes	Yes
Clive (Male, 73)	Lung Disease	Yes	Yes
Daisy (Female, 81)	Cancer	Yes	Yes
Emma (Female, 49)	Neurological Condition PSP	Yes	No
Frances (Female, 47)	Cancer	No	-
George (Male, 73)	Lung Disease	Yes	Awaiting appointment
Helen (Female, 89)	Cancer	Yes	No

The table given above lists the participants. A more detailed background to the participants can also be seen in Appendix 2. Five were not accessing hospice care, two had never been offered this support, two had been offered but declined any intervention, and one was awaiting his first appointment with a hospice nurse. I remained aware of this differentiation when analysing the interview transcripts because of its potential impact on the responses given. I will discuss the interview process in more detail later in this chapter after introducing the other two data sources: that of the organisational staff, referred to in this study as professionals, and the wider general public.

5.3.2 Organisational Staff Referrers

Another key group within the local population were organisational staff working in services who could potentially refer patients to hospice care. This is because their perspectives may influence patients' (in)access to hospice care. I included paid staff and unpaid volunteers who have the capability in their professions to refer patients to hospice care services. I have

referred to these staff as professionals because they are operating in a professional capacity irrespective of salary or position. Referrals may come from staff in healthcare settings but can also be from those working in other capacities, for example in secure settings, homeless services or adult social care services. It was important for this study to ensure a range of potential referrers was included to fully understand the perspectives of this section of the local workforce. Previous studies often only have participants who are professionals working directly within the health sector, however as anyone can potentially refer someone to hospice care, this study wanted to consider the wider workforce through other services and support, for example social care. These professionals can potentially work with people with life-limiting illness and therefore have some degree of responsibility for supporting their holistic needs. Having the ability and knowledge to know how to support and refer to appropriate care such as that provided by the local hospice, therefore, needs greater research and understanding.

5.3.2.1 Recruitment

There are many public-facing services which could have been included in this study. However, due to the time restraints and the project being conducted by a single researcher, careful consideration had to be given to selecting a sample of professions. Using knowledge of the local population and its needs, the following groups were identified, which I list below alongside a short summary explaining why they were included:

- Residential nursing care providers for older people. A high proportion of people with life-limiting illness are residing in nursing care establishments.
- Staff within charities that support people with learning disabilities. This demographic is increasingly living to an older age and more likely to develop life-limiting conditions.
- Staff working in organisations that support the homeless population. People who are experiencing homelessness are more likely to have multiple health needs and disabilities, and it is a significant part of the local population.
- Prison service staff. There is a large prison within the local area, and prison populations are known to be aging, and have inequitable access to health services
- Adult social care services. These services regularly work with the most vulnerable adults in the local communities.

- Primary health care providers. They work with local health needs on a daily basis and will have contact with patients who are registered as at end of life within their practices.
- Hospital staff within the palliative care unit. #The main provider of specialise palliative care.
- Hospice staff. The work at the only hospice serving the local adult population.

The response rate for returned questionnaires was very high, as can be seen in the table below, which may be due to the approach used for accessing and recruiting participants. Each source group was approached directly to explain the project and reasons why their involvement would be beneficial to the research. This also enabled me to establish a relationship with a key contact within the source group. The breakdown of respondents is shown in the table below:

Table 6: Professional Participants

Source of Participants	Coding Reference	Distribution of Questionnaires
Hospital	HS	5
GP Surgery	GS	30 (5 copies to 6 different practices)
Learning Disability Charities	LS	15 (5 copies to 3 different charities)
Adult Social Care	SS	10 (5 copies sent to local authority X2 occasions)
Nursing Homes	CS	30 (5 copies sent to 6 different homes)
Homeless Organisations	XS	14 (5 copies sent to 2 different charities and 4 copies given out at local homeless event)
Hospice	WS	18 (distributed by hand to various staff)
Prison Service	PS	15 (5 copies sent to 3 prison contacts)

For most of the sources, that key person took responsibility for distributing the questionnaires. Each questionnaire was sent out with the research information sheet and consent form (see Appendices 5 and 6), and a prepaid addressed envelope. This made the process of returning the questionnaire and consent form easier. Only the prison service proved difficult to get responses from and this is discussed in more detail under research challenges in the next chapter.

I used the coding reference to aid identification of the professional group and the responses that were received from the participants. For example, HS1Q1 related to the first participant from the hospital who answered question 1; WS5Q10 related to the fifth participant from the hospice answering question 10. These codes can be seen in the analysis and discussion chapters later in the thesis. The questionnaire used can be seen in Appendix 7.

5.3.2.2 Professional Sample

Recruitment for the questionnaires was ongoing throughout the data collection stage of the research. This enabled a great opportunity to achieve the response rate initially desired, and by the end of recruitment completed questionnaires returned were as shown below.

Table 7: Professional Sample

Source of Participants	No. Completed Questionnaires
Hospital	5
GP Surgery	5
Learning Disability Charities	4
Adult Social Care	3
Nursing Home	3
Homeless Organisations	5
Hospice	5

5.3.3 The General Public

The final group of participants to include was representatives of the local general public. As discussed, most research is undertaken with people who are directly involved with a service either as a patient, family/carer, or professional working in that field. However, I argue that attention is also needed among those who have no direct connection at present but might need care in the future. I contend if hospice care providers want to become more inclusive for their local population, it is important to hear the perspectives of the population that are not (yet) engaged with hospice care. The aim was to undertake three focus groups – two of which would be comprised of members of the general public and one group of residents within a homeless hostel. The homeless population was included because this geographic area has one of the highest incidences of homelessness within the UK. There is also a growing need for research into the inequity of health care provision for marginalised groups. This was a unique addition to my design which I wanted to include, as often research with the general population does not take account of this group; indeed, if they are studied, it is often in isolation from the wider population (see Chapter Three).

5.3.3.1 Recruitment of General Public Sample

The initial plan was to have two focus groups of volunteer participants from the local communities who were recruited locally. I used local Facebook community groups to promote and encourage recruitment. During my studies I realised how important the homeless community was locally and decided to include a focus group which allowed this perspective to be heard. This was achieved through engagement with local homeless charities including a hostel for homeless adult men.

The sizing of a focus group is important to enable conversation (Thomas, 2016) and to ensure all participants are included and enabled to participate (Krueger and Casey, 2009). My proposed range was 5-8 members for each group due to the sensitive topic of the discussion, and smaller groups may help conversations between the participants. I recruited 6 participants for group 1, 7 participants for group 2, and 6 participants for group 3; however not all participants attended.

After recruitment was completed the following focus group participants engaged and contributed to the focus group discussion sessions.

Table 8: Focus Group 1 Participants

Pseudonym	Gender	Age Band
Angie	F	45-54
Brenda	F	65-74
Cassie	F	25-34
Dora	F	65-74
Ed	M	35-44

Table 9: Focus Group 2 Participants

Pseudonym	Gender	Age Band
Alison	F	45-54
Bea	F	55-64
Celia	F	35-44
Debbie	F	35-44
Eric	M	18-25

Table 10: Focus Group 3: Participants Experiencing Homelessness

Pseudonym	Gender	Age Band
Aaron	M	18-25
Brian	M	35-44
Cliff	M	55-64
Dillon	M	25-34
Emile	M	25-34

Pseudonyms were given to participants to ensure confidentiality and anonymity, and those pseudonyms were used in the analysis of the data alongside the prefix FG- to illustrate which focus group the participant attended, for example *FG1- Angie* indicates Angie from Focus Group 1. More detailed profiles of the participants can be seen in Appendix 2. Different strategies were employed to collect the data from these three different sources, and these are explained in the next section of this chapter.

5.4 Data Collection Methods

The data collection aspect of the research initially focused on deciding what data would be required and how it would be collected to address the research question. When reflecting on the three groups of potential participants – patients, professionals and the general public - I tried to envisage what data collection method would be most appropriate to encourage and facilitate participation, and to collate the most effective responses for answering the research question. I also had to consider numbers of participants that would provide enough data for analysis but was manageable within the time frames of a PhD research project. I was encouraged by David and Sutton (2011) who noted that having a small well-chosen sample was more useful than a larger, badly chosen, group of respondents. I now discuss each group of participants in turn to explain the collection methods in more detail.

5.4.1 Patients and the Interview Method

I anticipated that including patients in this research would be the most challenging component of my data collection. This was because of two key points: the sensitive nature of the topic – reflecting on hospice care provision, and the patients' potential vulnerability – being in the last year of expected life. A semi-structured interview approach was chosen to enable participants to share their own perspectives with minimal guidance or restriction from less open forms of questioning. This approach was chosen as it suited the qualitative and inductive nature of the project. The semi-structured design of the interviews enabled some structure in relation to the questions that I intended to ask, and also enabled me to ensure they were similar to those used in the other data collection methods.

This approach allowed me to facilitate open and flexible interviews, adaptable where necessary due to the sensitive topic and the possible vulnerable situation of the interviewees, for example, if the interview needed to be carried out over more than one recording session. The openness also enabled participants to raise themes I did not consider in my interview guide, which could then be explored and developed during the interview, taking a more inductive approach.

I wanted to afford participants the time to discuss generally their background and care, with opportunities to bring into the conversation their own areas of interest, a technique which is possible within face-to-face interviews. These interviews also allowed me to show respect towards them as participants by offering my time, my presence and my ear to their voice. I wanted this interaction to be significant and meaningful for the patients. I valued being present to hear their perspectives, to be able to prompt for further details when required, and the opportunity to show immediate acknowledgement and appreciation for their involvement. This meant the whole process was patient led, with patients dictating when and where the interviews took place, and the duration of the interview itself. I wanted this autonomy for patients, not only to enable them to feel in control and therefore more relaxed and enable to participate, but also ethically it was necessary in order to prioritise their needs, particularly due to the debilitating health conditions that could be present.

There were risks associated with this semi-structured method, in that patients could find it easier to divert onto unrelated topics, so I needed to ensure my approach had strategies for supporting patients to stay on task, through prompting and redirecting conversation. There were also ethical risks that by having an open approach they may raise issues which were sensitive and could cause psychological harm. I therefore needed to be very aware of the patient's responses and how it was affecting them, so I could redirect the conversation if it became too upsetting for the patients or myself. These risks are connected to the ethics of the research project which are discussed in more detail in the next chapter.

5.4.1.1 Setting and Design of the Interview

Allowing people to talk in this semi-structured style enabled participants to provide greater amounts of information and deeper exploration of ideas (Boelk and Kramer, 2012), and so it was decided to that it would be the most effect approach to the interviews. While I created a guide for the interview in relation to areas that could be discussed (see Appendix 8) this guide had flexibility through the semi-structured approach for participants to frame their views and perspectives based on their own ideas and experiences (Cawley *et al.*, 2011). This approach allowed the socially constructed view of reality to be expressed by the participants (Hyden, 2014).

The location of the interview was an integral part of the design process. Considerable control was given to the participants because of their potential difficulties in mobility and communication. Therefore, interviewing at a place they were most comfortable was necessary and was determined to be the best approach in case they needed to have access to any equipment or resources such as communication aids, pain relief, or oxygen. Therefore, allowing them the option to choose the interview venue was crucial to ensure participation was not restricted. All participants chose to be interviewed at home, except one who requested the hospice setting.

A final aspect I considered was the duration of the interview. Again, the nature of the topic and medical conditions of the participants made this challenging because I had to be aware of their needs and the possible impact of being interviewed. This meant interviews could potentially last for an hour or longer but could also be undertaken in stages - small recordings done over a period of time in order to support and enable the interviewee to contribute fully. This impacted on scheduling the interviews, especially as I also planned to impose a restriction of one interview per week, to allow time for possibly having to revisit a participant in order to continue and complete an interview. This allowed time for myself as researcher to reflect and manage the potentially emotional and difficult nature of the interviews and topic material, and on a pragmatic level, also allowed for the transcription of each interview to be completed before the next was arranged. This practical element enabled analysis to be effectively undertaken very soon after the interview process as I utilised field notes during the interview, reflective notes immediately after the interview, and notes during

transcription. This was a strategy I likewise employed with the focus groups, but could not employ with the questionnaires as they were received over a considerably longer time period of over a year. The next section focuses on the questionnaire in more detail.

For this research I included a range of people from health and social care services, the prison service, and third sector organisations within the fields of learning disability and homelessness. Having worked professionally in health and social care before, I was keenly aware of the busy, often chaotic working environment and that trying to arrange face to face interviews or focus groups would be extremely difficult, and therefore not the most effective method of data collection.

Questionnaires and surveys are used for qualitative research as well as quantitative projects and have been successfully used in similar qualitative research into end-of-life care (Cheang *et al.,* 2016; Mackereth *et al.*, 2009; Papadopoulos and Lay, 2015). The use of surveys has been suggested as particularly useful for sensitive topics as they offer a greater sense of confidentiality for participants (Addington-Hall, 2007; Dickson-Swift *et al.,* 2019). To elicit the information I wanted from this cohort, I decided that a questionnaire would be most amenable to the working practices of participants; in that they could receive the questionnaire and complete it at a time convenient to them. This choice was suggested by the clinical consultant who assisted with the recruitment of hospital staff for this section of the research. Faced with the options of online or postal questionnaires I sought advice again from the hospital consultant. She advised that the postal format would be the most effective way of reaching staff within health settings. The consultant also stated that the paper-based option was essential. Her colleagues would find that easier to complete rather than an online or email version, because they were not all competent with technology, and the questionnaires on paper were more likely to be filled in while staff were on a coffee break at work. However, using this method did have some drawbacks. There was a workload associated with creating and printing the questionnaires, as well as the physical act of collating and posting them to the various gatekeepers I have identified in the different settings. Also, as the completed questionnaires were returned, there was the physical activity

of having to input the data into a digital format. There were also disadvantages to this choice in that I had no means to follow up on any of the responses given or be able to guide participants if they were unsure how to answer any of the questions.

An online approach would have eliminated a significant part of the recruitment work involved for this study. However, as it had been recommended by one of the key gatekeepers as the most effective method, this approach was used. Of course, using multiple sources may have also been useful, for example offering a choice of methods to participants including written, online, or an interview style face to face; however, with time restraints for the study it would not have been practical to have offered a range of collection techniques for the questionnaire. Also, by using the same format for all participants, it meant there was some degree of uniformity of data collection.

5.4.2.1 Design of the Questionnaire

The questionnaire required several sections of data to be collected. Information relating to the occupation or employer of the participant was required and therefore a tick box section was included at the start. This was so I could differentiate between responses from, for example, people working in care homes, and those from GP practices. I also included a simple demographics section to capture the participant's age, gender and ethnicity in case this information would prove relevant or useful to the analysis.

For the questionnaire itself, I adapted the questions from the interview guide I had already completed for the interviews, using a similar open-ended format of questioning. My reasoning for this was to aid the cross-analysis between data sources and to allow for consistency through the research project. The open-ended style of questioning used was to allow respondents to openly answer in their own words, with freedom to say as much as they wished. This resulted in a set of 10 open-ended questions, which can be seen in Appendix 7. Space was provided to enable the questions to be answered fully, with two questions asked on each page. This of course raised issues as it may indicate to participants how much was expected to be contributed as answers, and also it could make some participants feel uneasy if they were not able to answer any question fully. Open-ended questions may also be more

challenging and difficult to answer for participants, as opposed to closed questioning, offering multiple choice, or using answering systems such as Likert scales – all of which can be effective in a questionnaire format. However, I still decided it to be the most appropriate method for gaining insight into the perspectives of this group of participant's perspectives on hospice care, as any closed questioning style would not allow appropriate date to be collated that would be easy to analyse alongside the other data sources. The final method of data collecting was through the use of focus groups with the general public which is discussed next.

5.4.3 The General Public and the Focus Group Method

The final group in this research was that of the local population. While I was aware the patients lived in the local area, and many of the professionals taking part in the survey were also local residents, it was important to me to include the wider general population. Research undertaken into end-of-life care focuses primarily on professionals, family and carers, and to some extent the patients themselves (depending on their vulnerability and capacity) but it rarely considers the patients of the future; it is even rarer they are included alongside the views of patients and professionals. It is more than likely that there are people within the local population who will at some point require hospice care or have a family member or friend who does. How they feel about that care, and how they define it then is significant, and demanded inclusion in this study.

The justification for using focus groups to collect data from the general public was primarily due to the unknown background of my participants; I would not be aware of their past experiences. Not knowing how much previous knowledge or experience they may have of hospice care could have resulted in minimal information obtainable via questionnaire or interview. It was anticipated that through group exchanges, different levels of knowledge and experience could be shared and discussed. Other authors have agreed that focus groups are useful methods for collecting data, particularly in social sciences (Balasubramian and Read, 2012; Liamputtong, 2011).

Focus groups are one of the main methods for gaining qualitative data, they are not, however without criticism. Davis *et al.* (2019) for example, stated in their review of qualitative research

on randomised controlled health interventions, that focus groups do not allow for a deeper relationship between the researcher and the participants, that could be gained through a participatory methodology. Indeed, for these focus groups the design was very much about facilitating a group conversation between participants, with minimal intervention by the researcher. This enabled participants to discuss their perspectives and whether they are shared views or felt differently to others in the group. However, due to the varied methods used in this study, and the wide range of participants, it would have been much more challenging to have included participants more fully in the research in the participatory methodology Davis *et al.* (2019) advocate. There are other disadvantages to focus groups, such as poor management leading to one participant monopolising the conversation, groups diverting away from the topic being discussed, or participants failing to arrive at the required venue and time (Barbour, 2018), so I had to ensure I had strategies in place to manage these issues. Within a focus group however, conversations can be stimulated by other people's responses, can allow for debate and discussion of people's uncertainties, and reduce the perceived threat of a 1-1 interview situation (Simons, 2009), and allow the interaction between participants to be collected and analysed (Barbour, 2018).

Within each focus group there was at least one participant with direct experience of hospice care, either as a patient themselves or through supporting a family member or friend. This was not planned but became apparent during the focus group sessions. This meant they sometimes dominated the discussions, possibly because they felt more confident in being able to answer the open-ended questions, or because they were perceived as more expert or knowledgeable by the other members about the subject being discussed. Careful group management was required to ensure quieter, and less experienced participants could be included. I did not want any participant to feel less valued or that their responses were not important because they had not any direct involvement or experience of the hospice. As has been discussed earlier in this chapter, the perspective of the wider community was important and crucial to this study. Research into hospice care often does not include this voice alongside patients and professionals, even though realistically it would be the source of future patients. Having a diverse range of people actually also helped to give some internal validity as the groups were proposed as samples of the population, and therefore I did not want them to be comprised of similar ages or health care experiences. I was not aware of the ages and

experiences of participants prior to their involvement in the focus groups. Unfortunately, as I did not want to control the selection of participants in any way, I was not able to ensure a cultural or socio-economic diversity, an omission which was reflected in the final sampling used in this study.

5.4.3.1 Setting and Design of the Focus Group

As this was a localised study for Milton Keynes, I decided to source a local setting for the focus groups that was accessible and appropriate for the sessions. The university campus was considered as a venue, but this would have been difficult to reach by public transport and to navigate around the campus to find the venue for the focus group would have been problematic due to the size and layout of the site. Local venues were investigated as an alternative and a local community hall was booked for the sessions for groups 1 and 2. As Focus Group 3 comprised of participants currently experiencing homelessness and accessing services and support at a local hostel, I negotiated with the staff to be accommodated for the session to take place within the hostel setting. This enabled participants to attend in an easier way than if it had been at the chosen setting for the other focus groups, which was approximately five miles away from the hostel.

Each focus group was asked open-ended questions to help generate initial discussion. I used the interview sheet as a guide so I could ask similar questions to those used in the interviews and the questionnaires. This could then improve the analysis of the different sources of data because they are all based around a similar set of original questions. This was then followed by a vignette activity where the groups were given fictional characters to discuss in relation to their eligibility and access to hospice care. The decision to use this strategy was agreed as an effective strategy for this research, during a university supervision meeting. Vignettes are used in many areas of qualitative research, particularly as they are useful in time-constrained contexts, and for providing the *'elicitation of rich, detailed, frank conversation'* (Sampson and Johannsen, 2020, p.56). The reasoning for this activity was to encourage conversation around eligibility and access to hospice care. It was also to help stimulate conversation after the initial questions had been posited to the groups. The questions used and character vignettes can be seen in Appendices 9 and 10.

While the vignettes were fictional, they were based on the observed reality of the hospice environment and the local population. They were created to include fictional people with various life-limiting conditions, social, economic and cultural backgrounds, and who were living in different localised areas. Fictional vignettes are recognised as being inbetween the reality and imagined world as they are always influenced by the creator, their experiences and the purpose of the vignettes (Rabbiosi and Vanolo, 2017). This can be problematic for researchers; however, it would not have been ethical to include characters from real-life situations due to the risks of the participants recognising the cases (Sampson and Johannsen, 2020). The discussions around the vignettes provided a unique source of data around hypothetical hospice care patients. The techniques used for analysing that data are discussed next.

5.5 Data Analysis Techniques

Thematic analysis was deemed appropriate for my research as it can be adapted for a range of studies and is not restricted by any particular theoretical approach (Braun and Clarke, 2017). This form of analysis is a flexible way of exploring new data and emerging themes (Gray *et al.*, 2012). For this research it allowed an immersion into the diverse range of data sources used, but without losing the context (Lapadat, 2012), and is also noted as beneficial for internal triangulation between data sources within a study (Evers and Van Staa, 2012).

Thematic analysis is a broad term, often used to describe the coding and theming of data into categories and classifications, to derive meaningful results from research. It has been used extensively in qualitative studies, with researchers citing Braun and Clark (2006; 2014; 2017) as the key authors on this analysis method. Thematic analysis of qualitative data has been used widely in palliative care research including investigating perspectives within palliative care (Chapple *et al.*, 2005; Froggatt and Hockley, 2011; Powell, 2013; Sampson *et al.*, 2014). Thematic analysis requires a reflective attitude to the data and findings, incorporating a familiarisation with the data, creating initial codes which can then be grouped into larger themes for discussion (Braun and Clark, 2017). All of these factors determined the appropriateness of this analysis technique for this research.

In this project each data source was analysed as a discrete embedded unit, followed by an analysis of all the data holistically to uncover any congruences or disparities. This is possible because the design of the project allows each data set to be identifiable with a specific group of participants, and as such provides a rich source of data in itself. Analysis was undertaken at various stages during the research adopting an inductive approach. During the data collection itself, fields notes were made where appropriate of any key points. Immediately after each data collection activity more fields notes were made reflecting on the data, and initial thoughts about those responses. The data and field notes were then transferred onto the secure university database which necessitated transcribing the interviews and focus groups and inputting the questionnaire responses into an Excel format. This afforded me more time for analysis and reflection as this was completed.

Finally, when the data were all available collectively through the use of the software nVivo, a more in-depth analysis could be undertaken in conjunction with the field notes collated earlier. This was undertaken sequentially, focusing on each individual source of data first, and then a collective analysis of the whole data set after that initial round of coding of the discrete data units. This process of data analysis was effective due to the multiple stages of exposure to the data, and time afforded for reflection when working with that data. This enabled significant field notes alongside the coded data on nVIvo which could be analysed collectively.

NVivo is a common tool in research and helped immensely in sorting the large quantities of data effectively. There are some negatives to using applications such as NVivo: there was an initial period of trying to understand and navigate the tool which was difficult as it is a complex program. It also does not provide for any interpretation of data, which has to be done independently and then included in the data within the application. Researchers do, however, support using technology for data analysis (Sampson *et al.*, 2014), especially as it can aid visualisation and presentation of findings for dissemination to a range of audiences. Visual representations of the codes and themes generated from the data can be seen in Appendices 11-13. Generating the themes involved considerable reflection and analysis as many of the codes were easily transferable between the themes. However, going in-depth into the data itself, the final themes were considered to be the most appropriate and reflective of the content of the data. This was true of the individual embedded units of data in this research, and then collective analysis of all the data sources. NVivo enabled storage not only of the data

itself, but also relevant literature, notes and personal reflections, thereby allowing all this material to be used throughout the research, improving the validity, which I expand on next.

5.6 Validity

Acknowledging validity is important for any research to ensure it is a reliable and credible source. In this research project the findings could potentially be of interest to other environments and populations certainly within the UK and possibly other countries where hospice care is delivered. However, qualitative research is often not considered to have generalisability because of the individual nature of its participants, and the uniqueness of qualitative data compared to more quantitative studies. Indeed, this issue of the lack of generalisability is true for all qualitative research in general, but then the research is not intended to provide a generalisable statement, but rather improve understanding of complex, human experiences:

'Qualitative researchers seldom worry explicitly about the issue of generalisability. The goal of most qualitative studies is to provide a rich, contextualised understanding of human experience through the intensive study of particular cases' (Polit and Beck, 2010, p.1452)

This means there is less focus on external validity for qualitative research, and validity for is evidenced more through internal verification.

5.6.1 Internal Validity

I have adopted an approach where I am using multiple sources of data which are brought together in the analysis. This provides the study with a form of internal validity as the data are used to triangulate findings with each other. Triangulation is an integral part of data analysis and an area in which there is consensus on its usefulness in validating research. Internal validity is also strengthened by the type of data and how it is analysed (Yin, 2014). A strength of this study is that there is a greater depth around the background and historical context of the research topic, due to the wider range of perspectives I have brought together. This approach has created a complex insight into the research question, and therefore

provides a clearer understanding of the perspectives of hospice care (Eckstein, 2000). Validity was also strengthened by the research design facilitating participants to offer their own perspectives and to lead the research direction, particularly in the semi-structured interviews and discursive focus groups, but also in the open nature of the questionnaire design. This allowed new ideas and concepts to be introduced by participants which were not necessarily considered by myself prior to the data collection stage. his internal validity is often considered one of the strongest validation methods (George and Bennett, 2005).

Ensuring the research was accurate, fair, ethical and valid were all key points throughout the study, and using reflective practice helped to consider issues with the ethics of the research, as well as broader challenges and difficulties that arose during the study. These are considered in the next chapter where I reflect on myself as a researcher, and the research study process.

6. Reflection on the Research Study Process

Reflexivity has become an expected element in in social science qualitative research (Borgstrom and Ellis, 2020; Ortlip, 2008), and *'is a process that permeates the whole research endeavour'* (Dodgson, 2019, p. 221). Reflective practice, that is, thinking and evaluating experiences retrospectively (Boud *et al.,* 1985) is used extensively by practitioners in many social care fields in which I have worked. Therefore, my background meant that I had the necessary skills to support regular reflection and I employed the use of notepads and blogs to record my thoughts and emotions. These were used reflexively throughout the study, and I have included personal reflection from these journals in this thesis to inform this chapter. I start by reflecting on my own background, and then reflect on the personal difficulties which arose during this study. I follow this with a reflection on specific research challenges I encountered which were: the recruitment process, my interaction with participants and their data, and finally the ethical process and obligations for sensitive research.

6.1 Professional and Cultural Background

I was keenly aware this research was likely to affect me emotionally and psychologically. While I had no direct, personal experience of this hospice, I was aware of how researching a sensitive topic could impact on my own emotional and psychological wellbeing. Research into death and dying is often labelled as sensitive. Lee (1993) defined and categorised sensitive research into three areas. The first two areas are relevant here; his first consideration was related to topics that are considered private or sacred such as death. His second area concerned researching themes which may experience stigmatisation, which as discussed in this thesis is highly relevant for researching death and dying. I was also aware of how my own circumstances and background, my biases and assumptions, influenced me as a researcher. For example, from my work in care homes I perceived that there was a lack of knowledge and training for staff in caring for people at end of life.

Professionally, I had previously learned skills in reflective practice during my employment in education where both reflection-on-action and reflection-in-action are key components of effective teaching practice (Schon, 1983). This meant I was able to consider how undertaking

this project could impact on myself, and how I might impact on the research. I was able to recognise during the research when my own assumptions or values were influencing me. For example, I remember feeling frustration when I interviewed patients who had not yet been offered any support to meet their non-medical care needs, such as support for family members. Before and after every interaction with participants, I sought time to write and reflect on the situation, and therefore these reflections in this section took place at various points during my research.

Having limited experience of hospice care personally and no prior connections to any hospice, my initial knowledge was similar to some of the participants included in this project. My bias and assumptions influenced my thoughts and understandings connected to my own interpretation and socially constructed view of the world and what hospice care was. For example, I know I have a strong sense of fairness and justice, and struggle with the possibility that not everyone is treated fairly or has access to the same resources and services, such as hospice care. This was important, as I needed to unpack my assumptions and expectations, my 'emotional baggage', to ascertain how much it enlightened or distracted me during the research (Woodthorpe, 2009).

Our background as researchers is therefore important. For example, understanding our place in society with regard to power and privilege (Muhammad *et al.,* 2014) or the impact of being a mother (Nollaig and Holt, 2014). As a white native English woman, I have been influenced by societal understandings of end-of-life care within the Western world such as who is responsible for delivering that care. I have worked within social care settings where the biomedical model's focus was more on curative and reactive models to health dominated practice, such as interventions when someone becomes ill in order to make them well again. While I had no prior involvement professionally with hospice care, I came into this project with significant knowledge about end-of-life care generally having worked professionally within care settings for several years earlier in my career. However, it was still confusing to me; for example, hospice care was also referred to as a specialist palliative care service, and staff also took on the role of being specialist palliative care providers. I was not aware of the existence of any other, more general forms of palliative care, so the terminology was distracting and unhelpful for me as a researcher.

Most recently I worked to ensure ethical and fair treatment for people with serious health conditions including those considered to be at end of life. It is my experiences and connections with people who were dying which made me aware I needed to be reflexive throughout this research. This enabled me to be more prepared than other researchers undertaking studies around sensitive topics (Fenge *et al.,* 2019) because I was aware of my professional familiarity with the subject topic. Dean (2017) noted this importance when the subject being researched is close to the researcher's own professional or personal experiences. I agree with his positioning that reflexivity is, therefore, much more than merely talking about oneself. I now consider those personal experiences.

6.1.1 Personal Challenges

I engaged in significant reflective practice during my studies to help manage the emotional challenges of undertaking research at doctoral level. There has been extensive research into these issues (Bloor *et al.*, 2010; Levecque *et al.*, 2017; Storrie *et al.*, 2010), and so I was aware of this at the beginning of my research and wanted to ensure I developed the resilience and support network I would need. I experienced the emotional rollercoaster (Morrison-Saunders *et al.*, 2010) that many students describe when reflecting on the highs and lows of the PhD process. However, this was exacerbated by personal issues through the course of the study. When I commenced my studies, I was already a 'sandwich carer' with a disabled son living at home and my parents who lived nearby and who both having life-limiting conditions.

During the third year of the project my mother died leaving a large hole in my life, and significant problems for my surviving father who then placed much greater demands on me practically and emotionally. It impacted considerably not only on the progress of the research, but also my own attitudes to death and dying, and accessing support and care in the final stages of life. I was particularly surprised by my own inability to consider the concept of end of life for my mother days prior to her death or even in her final hours. On reflection after her death, I realised it caused a sense of guilt in that, as a former practitioner and current researcher in end-of-life care, I should have been able to identify this stage in her illness trajectory and provide more appropriate care and support. This impacted on my ability to continue my studies while I handled this difficult period and processed those emotions.

There is literature supporting the need for researchers to be prepared and emotionally resilient prior to studies (Muhammed *et al.,* 2014: Fenge, 2019). This is important, as not only collecting the data, but the analysis process afterwards, can potentially reactivate any prior trauma for a researcher because of that connection to our own personal experiences (Tilley *et al.,* 2021). However, there is significantly less written on managing trauma and emotions during studies due to events outside the research itself, such as personal loss (Borgstrom and Ellis, 2020). Kumar and Cavallaro (2018) consider not only how background and previous experiences shape researchers, but also the impact that traumatic events may have on a researcher if they occur during the research process. They created a conceptual framework for researcher self-care, as they believed there was less focus on the impact of prior trauma and trauma during the research process on researchers, than the consideration given to protecting participants. Whether that trauma is expected, or unexpected, there does need to be support in place both from the institution where the study is based, and from the researcher themselves. I found my own grief challenging to manage alongside the project, and at times found it very emotionally obstructive to conducting this research.

While I was aware my mother was likely to die during this project, I could not anticipate the consequences, was not prepared for the aftermath of responsibility it created for myself within the family role, and the emotions it would, and continue to produce in the following months. The loss has changed me, as I feel very different to the person I was before her death at the start of this research. My attitude to death hasn't changed, but I feel more connected to those who are bereaved or are caring for someone with a terminal condition. I also feel more aware of the difficulties of identifying dying within a person who has a terminal illness. These personal challenges all impacted on how I managed to continue my studies during some difficult times, however I also experienced challenges from the research itself, which I consider next.

6.2 Research Challenges

During this research I encountered numerous challenges, which affected not only the progress of the study, but also how I saw myself as a researcher, and the skills required to

undertake research. I summarise these by firstly considering the ethical process, and the ethics of undertaking sensitive research with vulnerable participants. I then reflect on the issues experienced during the recruitment stages of the research. I end the chapter by addressing the challenges that arose from my interactions with participants and their data.

6.2.1 Reflection on the Ethical Process

As a new researcher embarking on her first research assignment for a PhD programme of study, I admit I was naïve and ignorant about research ethics in general, and the process of gaining ethical approval. I focused on my methodology; on background reading; on learning as much as I could about my subject; and preparing my research sites to make a smooth, quick transition into the research field once my research proposal was transferred through probation to PhD candidature status. I did not realise that the ethics application process would take so much time, research, collaboration and emotion.

Notwithstanding the moral obligation to undertake safe and ethical research practice, due to the subject matter of this research and need for human participants I also required ethical approval from the university, the NHS and the Prison and Probation Service. Various documents were needed to justify the research to the ethics committees including guidance on plans to address any ethical concerns. I had to liaise with several stakeholders both within and outside the university and manage the emotional challenges that came from trying to navigate an ethics process within the NHS system, which is not designed for qualitative research, and not designed for researchers working outside of the NHS.

Research committees are the gatekeepers to research – often considered a hurdle to be jumped over in order to get on with the practicalities of the research itself (McLoughlin, 2010). However, such committees, boards and review panels are also there to help researchers develop skills in creating ethically sound research which supports and protects everyone involved, including the researchers. Indeed, as a researcher based within the university, there is the expectation and requirement that any research with human subjects will meet all ethical responsibilities. That said there have been concerns that research ethics committees may be reluctant to grant approval for research in palliative care, because of this vulnerable

population, and that the committees themselves may not be familiar with the specific issues and challenges connected to palliative and end-of-life care research (Gysels *et al.*, 2013). The process of gaining approval was a difficult and emotional journey, which is daunting for a PhD candidate learning the ethical process for the first time. I had prior knowledge of ethical issues relating to working practices as I had spent time employed in adult social care across various roles supporting older people and people with disabilities. I knew about autonomy, mental capacity, and power relations, as well as concepts such as equity, equality, justice and fairness from my roles in mental health, disability and advocacy work. This then enabled me to create specific and practical ethical guidelines and protocols for this research project.

At a university level, the application for ethical approval was relatively straightforward; completing the documentation and supplying additional material such as consent forms and information sheets, which can be seen in Appendices 3-6. Once the panel had reviewed this, I had some minor changes to make before gaining a favourable opinion which allowed me to commence with the research. I obtained ethical clearance from the university first as it enabled me to commence work on some of the non-NHS recruitment and data collection methods. This planning proved astute as the NHS system did take several months to complete, and the process was markedly different.

The first stage was to be registered with IRAS – the Integrated Research Application System (IRAS) – a web-based application form where all information needed to be inputted and uploaded. This took considerable time as it involves a lengthy and detailed series of questions, some of which were difficult to understand within the context of my research, as the IRAS site is designed for clinical research within the NHS. Various errors were made due to a lack of understanding and lack of guidance within the IRAS system itself for users to help with navigation in the application process. This created delays to completing the form, and it was only by securing peer support from another student online who had recently completed the process, that I was able to finalise my application. Once complete it was then problematic to submit the application as I needed various verifications from the university, including CVs of supervisors and a named representative from the university staff who was already known to the NHS to act as a sponsor.

The panel review meetings for the NHS ethics take place at various locations, and I was able to request a panel that had experience of qualitative research, which reassured me that they

would be understanding of my proposal. I did not expect however that after getting to the meeting location that it would only last fifteen minutes, and of the eleven people there, only three would ask me anything about the research. Following the meeting there was then a period of email and telephone communication to address the various amendments and additions that were required to resubmit the application for approval. It was not made clear however that once receiving a favourable opinion from this review panel, I would then have to go through a second review with the Health Research Authority (HRA) which needed more documentation and explanation, but this time from a legal and governance perspective. I required significant support from HRA staff to work through the various stages, and the final agreement from the NHS therefore took over five months from the beginning of the application. That final agreement allowed me to approach NHS sites to initiate my recruitment, but those sites could still refuse permission for the research to take place with their staff if they believed it was not in their best interests to participate. The whole process delayed the research considerably. The final authorisations from the NHS and the university can be seen in Appendices 14 and 15.

I had more ethical permissions to obtain later in the research as I was finding it very difficult to access the NHS staff within the prison service, who I wanted to include in my questionnaire participant group. Despite contacting the health team early into the research and receiving positive responses, I was not able to secure the engagement with the clinical team in the prison. To try and resolve this, I then applied for ethical clearance through the National Research Committee (NRC) within Her Majesty's Prison and Probation Service (HMPPS). It took time to navigate the various bureaucratic pathways to eventually secure approval to enable me to approach non-NHS and non-clinical staff working within the prison as potential questionnaire respondents.

The procedure to gain ethical approval for this research was difficult, complex and time-consuming. I had no previous knowledge of the ethical processes involved in designing research and found the systems I had to navigate both complex and poorly designed for qualitative studies by non-clinical researchers. I did not plan enough time for this part of my research which caused anxiety and worry about falling behind in my studies and delaying completion of the work. However, I have learnt and grown significantly through this. It has forced me to give far greater thought and recognition to the impact of ethics, not just in terms

of the practicalities such as recruitment, access and consent, but also the areas of our own understandings, perceptions, assumptions and power that can influence our ethical decision making and how we 'do' our research. I will now summarise some of the key ethical concepts and how they related to this research in the next section of this chapter.

6.2.2 Reflection on Autonomy and Power

As discussed in this chapter, I was aware of the ethical concepts of autonomy and power, and so had considered how they may impact on my research. Autonomy is seen as having the power and freedom to make independent decisions. This would mean being fully informed of what options are available and the impact or consequences of those options (Kitwood, 1993). Principle Two of the university ethical principles considers informed consent and autonomy over involvement and withdrawal from the project (Open University Human Research Ethics Committee, 2014). This principle was addressed with clear guidance from both my university and the NHS in relation to how I informed participants about the research, and their involvement in the data collection stage. However, there were areas where adopting a more paternalistic approach was appropriate. For example, the recruitment of patients necessitated taking advice and recommendations from clinical professionals who knew the patients' medical history. They were able to recommend suitable participants who they believed would be able to manage the interview process both physically and psychologically. This meant the clinical gatekeepers held quite a degree of power over who was recommended for participation in the study, however ethically it was appropriate to use this method of recruitment to ensure the wellbeing and safety of the patients.

As the researcher, I also held a degree of power and authority within the interviewer-interviewee relationship and as such could exercise that power to stop proceedings, if for example I perceived that to continue might cause harm or distress to myself or the participant. Participants were advised they could leave the study at any time and did not have to answer questions if they chose not to, but I was mindful they may have found that difficult. I therefore made a conscious effort throughout the interviews and the focus groups, to assess and judge situations carefully when making decisions about when to probe further, move conversations forward, or when to end conversations.

As this research was focused on a specific geographically designated population, purposive sampling was a preferred method of recruitment to enable greater understanding from a specific, selected cohort of participants (Simons, 2009). For example, I chose specific groups of professionals to participate in the questionnaire, who were likely to have access to, and therefore be able to inform and influence, potential users of hospice services. Choice of participants is not connected necessarily with trying to provide a sample (Thomas, 2016) but instead to provide a means for a depth of insight in data collected from those selected. Therefore, this study could be classified as unequal as some communities were not being heard, but from an egalitarian perspective it can be justified as the research provided outcomes to benefit a far wider population, including those not heard in this study, which could then be defined as communitarian (Beauchamp and Childress, 2013). I reflect on those benefits, and also the minimising the risk of harm next.

6.2.3 Reflection on the Benefits of Participation and Prevention of Harm

Some participants will not see the findings of this study due to their life-limiting condition. This raised concerns about the fairness of asking for people to participate who will not see the wider benefits from their involvement. However, the benefits of participation may instead be in the expectation of longer-term improvements and changes in the future after they have died, that is, a form of legacy. Consequently, this may still be a positive outcome for the participant, and that potential for future benefit is a crucial outcome for research with vulnerable populations (Cooper and McNair, 2017). I was mindful that some participants were keen to have their voice heard and to make a difference in some way through their involvement. Therefore, there may also be benefits to participants in having an opportunity to be valued and heard (Blair and Scales, 2012). I ensured the purpose of the research was stated on the information sheets given to all participants, (see Appendices 3 and 5), and that participants were welcome to discuss the research further with myself prior to involvement. Participants were also invited to contact me should they wish to see the findings of the research once completed.

Part of the ethical process was to consider and minimise the risk of harm to my participants and to myself in undertaking this research. This related to the university ethical principles

which stated that risks of harm for anyone involved, including physical and psychological harm, should be minimised (Open University Human Research Ethics Committee, 2014). The main area of potential harm in this research would have been due to the sensitive topic causing emotional and psychological distress, particularly due to the qualitative design of the study. To minimise this for the patient cohort of participants, I arranged for clinicians to facilitate the first recruitment stage, so they could recommend patients they knew directly and considered medically fit physically and psychologically to take part. This purposive sampling as discussed in Chapter Five was ethically necessary not just to ensure specific groups were targeted, but also to minimise risks as some patients may not be emotionally, psychologically or physically able to contribute without it potentially impacting negatively on their health.

Another strategy for helping minimise risk of harm was the use of a counselling helpline which was operated by Willen Hospice staff. All participants to the research were given the option to speak to someone should they find their participation caused distress. A final implementation was to ensure all participants were aware of their right to withdraw from the study at any time, which was explicitly stated on the consent forms and information sheets. With all this in place, to reduce harm from participation, I now consider the challenges I encountered during participant recruitment.

6.3 Recruitment Challenges

Recruitment began very early into the research as it was anticipated that it could be challenging to recruit the various groups required. The following section describes some of those challenges and how they were resolved.

6.3.1 Patient Interviews

Clearly patients using end-of-life care services needed to be included; however, I wanted to ensure there was involvement of patients who were not accessing the hospice services as well as current hospice patients. The recruitment took considerably longer than planned and did not result in the anticipated 10 interviews, only receiving three referrals from the hospice in

the extended data collection period. The reasons for these difficulties were uncertain; however, as I was reliant on professionals to gatekeep and provide access to appropriate patients I was also dependent on their timescales in providing appropriate potential participants for interview. I also had three patients withdraw from the study prior to interview, and two further patients had to withdraw due to ill health. Another patient did not want to be audio-recorded, which meant he could not participate as this was my means of recording the data. The recruitment process ended early into the third year of the study because of the time constraints of the PhD programme, to allow time for analysis and writing up the research, with eight patients having been interviewed by that stage.

6.3.2 Organisational Staff Questionnaires

The questionnaire was used to collect the perspectives of professionals. The background reading for the study had already identified the various gaps in provision for marginalised groups such as people experiencing homelessness and learning disabilities. Contact was made with professionals working with some of these groups within the early stages of the project, but I found many organisations contacted did not respond to requests made either through email or telephone contact. Others who initially sounded positive, later stopped communication and engagement further with the research project, causing unexpected extra work to source alternative organisations during the data collection stage. This impacted on the timescales and created more work than was anticipated because of the ongoing work throughout the project to chase questionnaire responses, particularly due to the considerable number of organisations targeted.

Data collection had to be stopped after three months into the third year of the project to allow time for analysis and writing the work up, even though the full quota of responses originally anticipated had not been reached. At that time no responses had been received from the prison service, and some of the other sectors had submitted less than five responses. When data collection ended, the total number of responses received was 30, which was deemed enough for the purposes of the research.

6.3.3 Focus Groups

These proved to be the most difficult participants to reach because my aim was to coordinate a group of diverse people from a local community. This can be challenging especially when dealing with the subject of death and dying; considered by some as taboo. It is also difficult as people naturally make assumptions when you approach them about such a request. For example, when I contacted community groups, charities, and places of faith, they invariably thought I would want a collective that had experience, either professionally or personally with end-of-life care. Assumptions were also made that they should be older people, inferring that younger people would not be interested, or would not be able to contribute to a discussion on dying. More issues arose as I found that people were often reluctant to commit to a meeting even though they showed a general willingness to help with the research. I then had difficulties maintaining that contact and finalising recruitment of focus group participants, arranging mutually agreeable dates and venues. This was frustrating as I was determined to include the general public perspective in this research. Ultimately it took several different angles and avenues to source the participants including using my various contacts within the Milton Keynes communities to try and arrange the focus group meetings.

Initially, I wanted to involve one of the many ethnic minority groups that are present locally and had established a good contact within the Tamil community. However, once ethics was approved, the contacts were not as responsive. I was not able to finalise a focus group from this minority group due to lack of response after the initial communications. I contacted community workers and local charities to support access to other ethnic minority populations, but I had no positive responses back. This was disappointing as I was aware of the ethnic diversity within the local population and wanted to include this as part of the research. I also wanted to include people from one of the more deprived localities and attempted to recruit through a local community-led Facebook group. However, the community event that I was invited to for a recruitment drive was cancelled due to bad weather and was never rescheduled. Alternative sources of participants were identified through Milton Keynes Healthwatch, a local public health organisation which facilitates many different participation and support groups, but that was not effective either. Recruitment was eventually successful through contacting an online social group for people within a local community area in Milton Keynes. This provided enough participants for two focus groups.

I also found a local homeless hostel accommodating to the research proposal and subsequently agreed to help facilitate a group of residents to participate in the group. The recruitment was still challenging however, as the residents have transient lifestyles and therefore planning activities in advance is difficult. I therefore had to arrange the session very quickly to gain the best response from the residents. The hostel is for men only, so I was conscious that women who are homeless in Milton Keynes have not been heard in this project.

6.3.4 Challenges with Participants

Due to the topic nature of the research, I knew this would be a challenge to manage psychologically. While I had prepared myself by researching emotional resilience and ensuring I had support from my university and wider support circles, I still found it emotionally challenging to conduct the data collection and analysis. This was particularly true for the interviews I conducted with the patients within the last year of life. One patient appeared to not be aware of his prognosis during the interview. This caused me concern as I wasn't sure whether to continue the interview, but thought if I stopped, I would need to explain my reasons. Secondly, I wasn't sure if he had not been informed, or had been informed but had not understood the conversation, or not agreed with the prognosis. The criteria for inclusion were very clear, and all patients were referred by practitioners who knew their medical history and condition, so because of this I decided to keep the patient interview as part of the research because it was still important to include his perspectives. However, it did make me feel uncomfortable being in the interview in this situation.

I had a strong connection with two other patients because they were women of a similar age to myself and had children of similar ages to my own sons. I found it difficult not to consider how easily this could be me in their situation, especially when they recalled their background and how their conditions had just developed with no precursor or reasoning. As a mother I also found it emotionally challenging thinking about their children and how they would be managing their mother's terminal condition. My feelings around these patients were actually strongest when I was transcribing and then analysing their words, as hearing them in detail meant I was forced into their world, and it took me considerable time to complete these tasks.

I had to take several breaks and share my emotional responses with others to help manage my emotions and my research work during that period.

Similar challenges manifested as I progressed through my research and was informed by the referrers when patients had died. Having that knowledge affected me again emotionally, especially when I was revisiting the data and analysis towards the end of my PhD. Hearing the words of people who have since died is an incredibly intense experience, especially when they are talking about their own difficulties and attitudes towards care and support for themselves and their families as they near death. I remember particularly those two ladies with immense feelings of gratitude, respect and also some sadness when I consider the gaps in their care. It made me appreciate how emotive and 'human' research can be, and that we must remember we are all human, researchers and participants alike.

This chapter has considered how important, and useful reflection has been throughout this project. Not just in terms of myself as a researcher, but also to evaluate and manage the issues and challenges that occurred. Those challenges were a combination of factors outside of the research, and also from within, such as the ethical and recruitment processes. No research project can be expected to go as planned, and reflecting on each problem, enabled a greater flexibility and adaptation to progress the study to completion. That reflection and adaptability enabled significant findings to be found in the data that was collected. The next three chapters focus on those findings from each data source in turn, beginning with the questionnaire responses.

7. Findings: The Perspective of the Professional

This research is investigating the perceptions of a population about hospice care provision, and therefore several sources of data were required to give a wide range of perspectives from different stakeholders. This chapter and the following two present the findings from organisational staff, referred to in this study as professionals, who work directly with clients, the local general population of Milton Keynes, and patients who have been recognised as in the last year of expected life. As noted in the methods, the data were analysed thematically, and those themes can be seen in Appendices 11-13.

As discussed in Chapter Five, it was considered important to include the perspectives of professionals and practitioners who work directly with the public, either in a paid or voluntary capacity. These were included because, should a person be diagnosed as terminally ill, it is possible for professionals to refer a patient to the hospice, including those professionals who may be supporting them for non-medical reasons.

This chapter focuses on the findings from participants working within Milton Keynes that could potentially refer their clients to the hospice service, if required, through that direct contact. These findings are from the analysis of data from the questionnaires that contained ten open-ended questions for completion which can be seen in Appendix 7. Key people within organisations were contacted prior to sending out the questionnaires, and they encouraged staff and colleagues to complete the questionnaires and return them in a timely manner. This meant most questionnaires were returned, with the exception of those sent to the prison service.

The findings are discussed alongside responses from participants who completed the questionnaire. These responses were coded to enable identification of the question being answered, who responded, and their profession. For example, LS3Q6 indicated it is the answer to question 6 from third respondent from the learning disability charity. As a reminder, the codes for the different sources of respondents are as follows:

HS-   Hospital staff

GS-   GP surgery staff

LS-	Learning disability charity staff/volunteers

SS-	Adult social care staff

CS-	Nursing care home staff

XS-	Homeless charity staff/volunteers

WS-	Hospice staff/volunteers

This chapter is structured thematically using the themes which emerged through the analysis process. The main theme relates to the level of knowledge expressed by respondents about hospice care. This is because, upon analysis of the questionnaires, it was noted that there was a high proportion of responses which were either blank (11 occurrences) or gave reasoning such as 'don't know' (18 occurrences). This totalled 29 responses across the 300 completed separate answers from the 30 questionnaires that were returned for analysis. This comprises nearly 10% of the data collected. There are several reasons why a respondent may leave a question blank; for example, they may not have had time to complete it, or may have been unsure of what, in their perspective, would be a correct answer. However, openly stating they do not know the answer, strongly suggests a lack of knowledge. This theme is presented first, followed by the other identified themes which are: the physical location of hospice care, time, the perception of the specialism of hospice care, and the final theme which relates to the hospice brand reputation locally.

7.1 Level of Knowledge

The nature of a questionnaire is that participants have the freedom not to answer questions, and this was seen across the responses to all 10 questions. Most significant were the lack of responses of professionals from non-health organisations, that is, the learning disability charities, nursing home staff, homeless charities, and adult social care staff. Some provided the reasoning for not being able to answer as not having any direct experience of hospice care. This is, in itself, interesting as all respondents were in positions where they could potentially refer people for hospice care, irrespective of having any experience of the service. This belief that they had no direct experience of hospice care and therefore were not able or

qualified to discuss it on the questionnaire could suggest they may also not feel comfortable or able to discuss it with any clients they are working with. This clearly demonstrates a stark difference between the theoretical assumption that anyone can refer patients to the hospice, and the reality that in practice, they do not. This was seen in the three months of referrals data where no referrals came from outside of healthcare practice. This data from the questionnaires may help to explain why this is the case.

Nearly all the respondents (total of 26 out of 30) believed that to access any form of end-of-life care including hospice care, a referral was needed from a health professional often citing GPs, but again there was some uncertainty around this. For example, when asked 'How do people in Milton Keynes who need end of life and/or hospice care access it?' participants who were not from health backgrounds gave responses which appeared to lack confidence in their answer, but offered suggestions as to how they believed patients may access care:

> *'I'd imagine there is some end-of-life pathway, referral system in place'* (LS3Q6)

> *'No idea – I would have thought a GP would refer'* (XS3Q6)

There was a lack of respondents acknowledging that they could refer people into hospice care directly themselves as part of their role as no-one appeared to know this was possible, which included the respondents from the hospice. This latter group also represented the only participants who were aware of the option of self-referral for patients when answering this question. This demonstrated a lack of knowledge of the referral process and their ability in their own roles to undertake this for their clients.

Respondents seemed very unsure as to how to answer questions on how hospice and end-of-life care was delivered locally. When asked to explain how they felt this happened, eight acknowledged that they did not know, and another eight participants gave off-topic responses not directly answering the question itself, such as this primary care professional:

> *'I am pretty happy with the provision of end-of-life care'* (GS4Q7)

Another respondent did not answer the question relating to what care the hospice provides, because they perceived their lack of experience meant they could not respond accordingly:

'I have no experience of end-of-life care in Milton Keynes' (XS3Q8)

This could indicate that having no experience of hospice care was perceived to be equated to not having the knowledge or expertise to answer the question. It raises the issue of whether experience is the only way that people learn about hospice provision. When asked how hospice care is delivered locally, nearly a third of participants (nine) expressed they did not know or left the question blank. Unfortunately, as this was a questionnaire there is no way of determining why some responses were left blank, and this was seen with several questions. However, the admission of not knowing by some respondents does demonstrate a lack of knowledge and understanding about the care hospices provide:

'I have not had direct experience however heard families pleased within Willen Hospice' (SS1Q8)

The respondent here is resorting to assumptions that it must be good, due to the reputation the hospice has locally, but without clarifying any idea of what the specific care is, indicating they may not have such knowledge, and are reliant on experience to acquire such knowledge. There were misunderstandings around eligibility for hospice care. When asked about how hospice care is delivered locally one respondent stated:

'I only know Willen Hospice as cancer patient with less than 14 days of life' (CS2Q8)

Most respondents knew hospice care was provided by the local hospice but could not explain in any detail who was eligible, apart from the connection to cancer care. The perceived specialism of cancer care expressed above was also noted in the findings from the other data sources (see Chapter Eight and Nine) so is a potential issue for hospices.

However, respondents did consider how to address this lack of knowledge. When asked in Question 10 about how hospice care could be improved, there were a few responses which

supported the idea that the hospice needed to promote itself to educate the local population, to improve people's understanding of hospice care. This could then affect an improvement in care. A learning disability professional commented:

> *'communication with people to let them know exactly what they do, as this is not known'* (LS2Q10)

A range of respondents commented similarly in response to this question that they perceived hospice care could be improved by increasing awareness specifically in relation to the work and support provided. This perceived need for educating the local population could be used to target specific perceptions. For example, a hospital professional explained they believed it could help to dispel the myth of the hospice being a place to die:

> *'the hospice needs to work harder on its supporting life image and to overcome the misunderstanding of its role as a place to die and nothing more'* (HS4Q10)

What can be seen from the responses then, is firstly a lack of understanding and knowledge in respondents, demonstrated in their blank and 'don't know' responses, followed by several respondents acknowledging their lack of knowledge of hospice care, and highlighting the need to educate and communicate more effectively with the local population, including professionals and practitioners. The second key area is shown in the second theme from the findings from the questionnaire data, which focuses on the physical location of hospice care.

7.2 Physical Location

Respondents were asked in Question Two to state what hospice care meant to them. In response, the participants overwhelmingly seemed to refer back to the physicality of the hospice, that is the physical building and the inpatient service provided there. This was a dominant theme with 50% of respondents mentioning a physical place. For example, a professional working with people with learning disabilities, and a primary health care professional stated:

'the care one gets in an institution specialising in looking after terminally ill patients' (GS4Q2)

'a place where people can go to die, where they can manage care, support and pain management' (LS2Q2)

Whether this perspective was due to their own experiences, or from how hospice care has been promoted locally is unclear, but it was significant that they viewed hospice care as solely being within the confines of the recognised building. The connection to a physical place was demonstrated as they talked about the hospice being a place, an institution, and was similarly reflected in other responses. This perspective of the physicality of care was also demonstrated when respondents were asked in Question Three if there were any differences between end-of-life care and hospice care. Over a third of respondents (11 out of 30) answered spatially, with the remaining 19 either not answering, stating they did not know, or citing lack of experience and knowledge to be able to give any clear response. The 11 respondents who answered spatially believed hospice care was only delivered within the hospice building, and end-of-life care was given either in the hospital or at people's homes. By placing hospice care within a physical place designated as a hospice, it removed the consideration of that care being delivered in other locations such as a community setting or patient's home. Respondents working with learning disabled people, and people experiencing homelessness, saw this as a difference between end-of-life and hospice care:

'I think that end-of-life care can be delivered outside the hospice setting e.g., in individual's homes' (LS3Q3)

'one is in the home (end-of-life care) and the other a residential place (hospice care)' (XS3Q3)

The failure to perceive hospice care as a community-based service was also expressed by a professional working at the hospital when answering a question on what hospice care meant to them:

'patients with a non-curative, palliative illness who are experiencing symptoms as a result of this and cannot be managed in the community' (HS3Q5)

A nursing home professional also concurred that the place of care was a key difference with hospice care:

'end-of-life care can be delivered anywhere. Hospice care is specific to the environment' (CS2Q3)

What this shows is a misperception that hospice care cannot be provided within the community or any other setting; it can only be provided within the hospice building. If people perceive this to be true, it will certainly impact on access and inclusion as some potential patients may not feel able or willing to attend the physical location. This is particularly pertinent for this localised study. The local hospice in Milton Keynes is a difficult place to get to without private transport, impacting particularly on the poorer areas of Milton Keynes where there is less car ownership and higher levels of deprivation (see Chapter Two). More telling in the context of this data, is that potential referrers may not even consider offering hospice care as an option for people if they feel it would not be appropriate or accessible for them, for example people living within residential care facilities or who cannot physically access the hospice setting.

The hospice setting itself was mentioned within several responses to other questions, with respondents describing the setting. In Question Nine they were asked about their own personal views about the hospice, and concluded it to be a peaceful and 'good' place:

'it's positioned in a lovely place overlooking the lake, very calm and peaceful for patients' (GS2Q9)

'when I visited the atmosphere was good and the setting lovely' (XS1Q9)

The positivity expressed here by a primary health care professional and a homeless charity worker highlight what they assumed was a therapeutic landscape found in that environment,

and they associated hospice care strongly with the positivity of that physical setting. This positive environment was not mentioned when asked about end-of-life care more generally but was only raised when questioned directly about hospice care, suggesting it is strongly connected to perceptions of hospice care specifically, and can be seen as a form of topophilia.

When respondents were asked about how hospice care could be improved in Question Ten, they still referred back to this concept of the physical place. Five participants believed the hospice should expand its physical building to cater for more patients:

> *'possible expansion and more beds as bed pressures are often an issue'* (LS4Q10)

> *'Provision of more beds, recruiting more palliative care physicians/consultants'* (GS4Q10)

It is not clear why these professionals perceived this issue of capacity with the local hospice, as the hospice workers did not express the same need for expansion of inpatient services. It was only respondents who were from the hospice that that gave any consideration of care outwith the hospice setting, which is to be expected due to their direct contact and involvement within the hospice itself.

> *'more funding so they can enlarge their services to reach out to wider community'* (WS3Q10)

The 'where' question in defining hospice care was therefore a prominent theme, but the 'when' question was also a key identifying factor and this is discussed next.

7.3 The Time for Hospice Care

This next theme looks at how respondents associated the trajectory of a patient towards death with their definition of hospice care, and when they perceived hospice care should be delivered during that trajectory. In Question One respondents were asked what end-of-life care meant to them, to try and ascertain if a difference was perceived with hospice care. Out

of the total 30 responses, 13 demonstrated a belief that end-of-life care was about the final few hours or days of life, as shown in this answer from a participant from a homeless charity:

> *'Making a person as comfortable as possible in their last days either in hospital or their own home'* (XS5Q1)

The only exceptions to this were two participants from the hospice and the hospital who mentioned end-of-life care being part of hospice care and could therefore be provided over the course of a few months:

> *'Providing care and using skills and knowledge to help those within the last 12 months of life'* (HS4Q1)

> *'Health and support to make the most of the last few months of life'* (WS4Q1)

It could be expected that professionals from the hospice and hospital would be more knowledgeable about hospice and end-of-life care in relation to when care is given if it is part of their professional working environment. However, most responses around end-of-life care were generally connected to the final act of dying and that notion of achieving a 'good death' for example as a GP doctor stated:

> *'Patient dying - last few weeks or days usually'* (GS5Q1)

Respondents differed in their understandings of timescales for hospice care, although when asked on the questionnaire there were some blank responses or answers of 'I don't know'. Therefore, it was difficult to ascertain a consensus from the respondents. The findings did reveal a clear difference between the respondents, with the hospital and hospice professionals perceiving hospice care was for longer than end-of-life care as can be seen in these responses from a hospital and hospice professional:

> *'main difference is that hospices can care for people over longer periods'* (HS4Q3*)*

> *'(for) patients who have been diagnosed with a terminal illness but are not at the end of their life'* (WS4Q4)

It was generally perceived that end-of-life care was for anyone with a terminal illness and provided right at the end of life, often citing hours, days or possibly weeks. As end-of-life care uses the phrase 'end of life', responses demonstrated an assumption that end of life meant hours or days. Hospice care was considered to be for a longer time period, possibly weeks or months. This may be due to hospice care not having a time connotation attached to the terminology, so the timescale may seem as less clear for most respondents. Only staff from the hospice and hospital appeared to be more knowledgeable on this. The term hospice care was perceived by respondents to symbolise a specialism or expertise of care, which is presented as the next theme.

7.4 Specialised Care

Respondents were asked to clarify how they would describe hospice care. Some respondents explained that they believed it was a more specialised form of care. This was particularly noticeable from participants who were from health backgrounds. For example, hospital and hospice staff commented:

> *'a place to manage symptoms as a result of a terminal illness. Care is holistic and support psychological/emotional needs as well as physical'* (HS3Q2)

> *'those nearing end of life and need expert 24hr care and support'* (WS4Q5)

Having a health background was influential in the knowledge of hospice care as highlighted in this chapter, and these cohorts of respondents were able to mention some areas of provision such as psychological support. Participants suggested other possible services including respite care, day services and counselling, but over half (17 from the 30 respondents) were more generic in their responses about providing specialist support, care and time. They recognised it was a specialised form of care but did not explain further what they understood that meant. A respondent from a homeless charity noted that:

> *'hospices have the experience and time to be able to answer questions from their guests and families and support them in whatever is needed'* (XS5Q2)

While they noted that hospice staff were able to work with families to offer support, they did not explain what that support could be. Whether this is because they did not know or did not feel they needed to expand on the questionnaire is unclear, however this was also shown in other responses where the specialism of hospice care was mentioned, but not expanded on in any way. These responses may indicate that they were not aware of the specific forms of care that hospices can provide, but generally agreed it was a service that required, and delivered, expertise and experience.

That expertise was expressed by some respondents as supporting patients primarily with diagnoses of cancer. For example, when asked in Question 5 who receives hospice care, and in Question 8 how hospice care is delivered, professionals from a homeless charity and care home answered:

> *'those who are terminally ill, often with cancer'* (XS1Q5)

> *'as far as I'm aware there is only one hospice and that is for cancer patients'* (CS3Q8)

This focus on cancer among respondents supports the view that there is a societal assumption that hospice care is focused on cancer, indeed, this was prevalent throughout the findings of this research. This understanding could impact on whether these respondents would refer eligible patients with non-cancer diagnoses into hospice care. It could also cause some refusal of hospice care by patients and their families, if they perceive it is a hospice specialism and therefore the hospice would be less specialised in care for other terminal conditions.

There was some recognition that hospice care included supporting complex health needs. For example, when asked what patients receive hospice care, this social care professional stated:

> *'Patients who cannot be managed at home maybe because of complexity of care'* (SS2Q5)

This shows again the connection of the place, as shown in an earlier theme of this findings chapter. Here the respondent has linked the complex care requirement causing care to be

given in the hospice building, as it cannot be delivered at home. The care was also described as nursing, as this homeless charity respondent commented:

'Hospice care is usually a form of end-of-life care, when nursing care is needed' (XS1Q3)

More detailed responses came from primary health care and hospice staff, as could be expected due to their more direct contact and experience of hospice care:

'Hospice care covers a wider area than end-of-life care. It can include care for relatives, extended care for cancer or palliative cases who are not necessarily 'end of life' case' (GS3Q53)

'being there for the relatives as well as patients, that patients are free from pain, are comfortable, have any religious/spiritual needs met' (WS1Q2)

The data highlighted this difference between the health and non-health professionals in understanding hospice care, who it is for, and how it is provided. Overall, respondents were vague about what end-of-life care or hospice care actually was. hose that answered the question more fully agreed that hospice care was a specialised form of care that was undertaken by trained experts. However, there was a misunderstanding in relation to hospice care being primarily for patients with cancer, unlike end-of-life care which was identified for anyone with a terminal condition. There was again a clear difference between the more detailed responses from the hospice and health care professionals, and the other respondents. There was also a consensus among participants around the reputation of hospice care locally, which is the last theme identified and discussed next.

7.5 Perceptions of the Reputation of Hospice Care

Part of the questionnaire was designed to elicit views on how the hospice was perceived locally. This section was completed by all participants and there was a strong positivity and

high regard for hospice care. Many participants stated it was excellent, very good, or well received, for example a hospital professional and adult social care worker commented:

'Hospice care appears to be of a good standard; staff are experts in complex palliative symptoms' (HS3Q8)

'It appears to be well known and have a good reputation' (SS1Q9)

It is noticeable that even though many respondents did not offer any specific knowledge of the hospice, with many responses remaining blank or completed with "Don't Know", there was still this overwhelming positivity and high regard for hospice care and the local provider. It also acknowledged that this reputation was seen throughout the local communities, as these responses demonstrate:

'Very well thought of in the community, so many members of the public support and fund raise, thousands of people!' (WS1Q9)

'I think it is well respected and supported financially by the local community' (HS1Q9)

This positive and supportive attitude towards the hospice therefore meant some participants did not perceive that hospice care could be improved in any way, when asked in the final question of the questionnaire. A homeless charity professional responded:

'I don't think they could do much more' (XS5Q10)

The high regard for the hospice was not universally expressed however, and some professionals working in the health sector expressed some criticism of hospice and end-of-life care, particularly around a perceived variance in service provision across the locality. When answering the question about how care is delivered locally, a hospital professional and care home professional expressed:

'I think it's a bit of a lottery. For those patients who are known to hospital or community palliative care teams the delivery of care is well managed with evidence of good collaboration. Patients not referred in a timely manner may not get access to coordinated care or access to specialist advice and support' (HS1Q7)

'The scale is too large from exceptional to dismal' (CS2Q7)

The analogy of a lottery in relation to accessing care appears to relate to patients needing to be part of the healthcare system prior to hospice care intervention, and the need for appropriately timed referrals for when care is required. These may well also be reasons for the second quoted response above for Question 7. This question related to how they believed hospice care was delivered, and the response suggests they perceive the delivery of care locally varies significantly. This demonstrated an awareness among some of the respondents that care wasn't perfect, it could be improved, and that access and inclusion for the local community was not necessarily equitable.

The hospice was widely seen as an organisation that was very well supported and respected within the local community. This was linked in with the physical location and also the quality of the specialist care provided, evidencing a love, or topophilia of hospice care and the hospice environment. The hospice was described in very positive language, and the only suggestions for improvement were to increase its physical size, increase the funding so it could reach more people, and how it works collaboratively with other health providers. The only criticisms were from health professionals who may have had more direct working experience with the hospice care provision.

7.6 Summary

To summarise these findings, 30 different responses were received to 10 open-ended questions relating to end-of-life and hospice care. The data presented here demonstrated that the level of knowledge about hospice care was clearly limited, with many respondents acknowledging a lack of knowledge in answering some of the questions, and others being left

blank, indicating further a possible lack of knowledge. This included knowledge around what hospice care is, who is eligible, when and where it is offered to patients. There was a noticeable difference with the responses from people working in the hospice or hospital, and these indicated there were some issues around hospice care being accessible and inclusive. However, the fundamentals about hospice care were missing in the responses of many participants, indicating a real need for education within professional circles. That need was also seen among the other data. When responses were given, they did show a focus on the physicality of hospice care, a love of the physical setting of the hospice, and the high regard and love for the organisation and its staff. There were also some stigmatising aspects of hospice care, such as its connection to death and dying, which was connected to the concept of the hospice being a place to die, where people do not leave. This showed a fear, or topophobia around the hospice setting. The next chapter focuses on findings from the focus groups with members of the general public, where clear similarities between the themes can be seen.

8. Findings: Perspectives of the Wider Population

The previous chapter presented findings from the data collected from organisational staff working in the local area, who had direct contact with the general public. In this chapter the focus is on the perspectives of that wider general population that is the people who live within the geographic area of Milton Keynes. For the purposes of this research study, it was deemed important to ascertain their perspectives on hospice and end-of-life care, as this could be influential on their future care choices and preferences and is often overlooked in research into specific health provision.

As discussed in Chapter Five, focus groups were chosen as the most appropriate method to elicit the perspectives of this cohort. Focus Groups 1 and 2 comprised a range of participants who agreed to participate in the study, and the third focus group comprised adult males who had recently experienced homelessness and were temporarily housed in a shelter. The inclusion of the third group of men experiencing homelessness gave a breadth of perspectives including a significant and important part of this local population. The focus groups were recorded and lasted approximately one hour in duration.

The analysis of the data from the focus groups resulted in the identification of the following themes: provision of hospice care, the accessibility and inclusivity of care, accessibility, place, values and ethos, and finality. Each theme is presented in turn in before I summarise these findings at the end of the chapter. I start however with an overview of the noted differences among the participants.

While prior experience of hospice care was not a criterion for inclusion in the focus groups, it was apparent during the data collection that each grouping had at least one person who had some experience, either as a patient, relative or friend of a patient previously. Further details of that prior experience can be seen in the participant profiles in Appendix 2. This impacted on the dynamic of the groups as these participants were able to share their experiences and knowledge with the other members of the focus group. For example, Alison used her experiences of her own illness to shape her perceptions of care for people who are chronically and terminally ill:

'I have cancer so…. I've worked with the hospice a bit and what support they can give you and care for, and it's difficult, and…. A lot of people don't want to go through the chemo and the treatment and would like to give up. A very large percentage drop out to be totally honest, and don't want to take it any further, because it's vile. It's an absolute vile thing to be going through, and the pain, and the suffering you cause everybody else around you, not only with that anger that you have for yourself, because you don't know why you've got it, you just know that' FG2- Alison

Alison's response here shows some insight into the perceptions and influences of patients with terminal cancer. The option to give up, to not continue with any form of treatment could be influential in deciding whether or not to accept care and support from health professionals, including hospice care providers, and point noted in other research (Flaherty, 2018; Johnson Shen and Wellman, 2019). Alison also mentions the perceived psychological impact of knowing she was causing suffering in others seeing her advancement towards death, and the indiscriminatory nature of developing cancer. These factors need to be considered when offering support and care to a patient with a terminal condition. It demonstrates that dying goes far beyond the actual medical aspects of a body ceasing to function, and therefore that holistic care is crucial.

Another noticeable aspect of the focus group dynamic was that the younger participants under 30years of age were less vocal and when they did contribute, they acknowledged perceiving they had less knowledge than the older participants in all three groups. Emile in Focus Group 3 had never heard of the term 'hospice' and contributed very little to any of the discussion.

Interviewer: *Have you heard of the term hospice before?*

Emile: *I hadn't heard of it until today*

Aaron: *Ok*

Emile: *Yeah, never came across it.*

         (Focus Group 3)

Celia, the youngest participant in Focus Group 1 often asked questions or admitted she was not aware of some of the subjects discussed by the group.

> Celia: Isn't it only though to give families a break?

> Angie: No

<div align="right">(Focus Group 1)</div>

Eric in Focus Group 2 had some experience of the local hospice as his grandmother had accessed their care, and so was able to join in more with the conversations:

> 'Yeah, I guess until this conversation, I thought it was end of life and I guess that was purely because my grandma went into Willen as well, and she died there, and she was just, like, loads of things, like you know, when you get older, loads of things go wrong' FG2- Eric

This finding from the research where the age of the participant impacted on their knowledge and confidence in understanding hospice care is important, as terminal illness can impact on younger people, either through their own diagnoses, or those of family and friends. Including younger people in research into end-of-life care is therefore needed to ensure their perspectives are heard, and for a better understanding of how diverse generations may perceive hospices and hospice care differently. Also, there needs to be a consideration that the variance of awareness within local communities may be age-related, especially when currently the UK public health approaches, policy and practice, tend to homogenise the adult population.

This chapter now focuses on the resulting themes from the analysis of the focus group data, starting with the hospice care provision.

8.1 Perceived Range of Provision of Hospice Care

One of the primary questions for the focus groups was to ascertain their perceptions of what hospice care can provide for patients. There were several instances of confusion and uncertainty about different aspects of hospice care provision from all three groups of participants, even though the majority of participants in Focus Groups 1 and 2 stated they knew the hospice well. Eric in Focus Group 1 summarised this finding:

'I loosely understand that they mean making someone as comfortable as possible under the circumstances, but that might mean different things for different people in different hospices, I mean I wouldn't know exactly what that was' FG1- Eric

Focus Group 3 could not think of any tangible care provision that may be provided by a hospice, often just recalling it again as making someone comfortable.

Cliff: They [hospice] *are doing all the medical care*

Brian: *Being comfortable*

Aaron: *Yeah*

Dillon: *That's the main, that's how I understood it*

(Focus Group 3)

In Focus Groups 1 and 2 often it was one member of the group sharing their experiences with the rest of the group, as demonstrated in these exchanges:

Dora: *You were saying it was five months that you had someone coming from the hospice coming out to you…*

Ed: *Well I didn't know the hospice did that*

Brenda: *Yes they do*

Celia: *I didn't know either*

Dora:	I thought it was in the hospice
Ed:	Yeah
Celia:	I didn't know they did outreach
Brenda:	Yeah I think, I think there are more families out in the community

(Focus Group 1)

Brenda was informing the group about the hospice care her family received in their own home, as the rest of the group did not appear to have much knowledge about what was provided locally. This hospice at home service is a key component of what is offered by the local hospice and accounts for most of their work. It is notable that it doesn't appear to be more widely known by the general population. Alison informed her group about her experience of hospice care locally:

Alison:	It also gives respite to people who have long term issues that take up an awful lot of care from, from home
Cassie:	Oh ok
Eric:	Yeah
Debbie:	I didn't know that
Alison:	That is quite strange isn't it because I don't think a lot of people do realise…
Cassie:	Yeah
Alison:	…That you can have respite at the hospice

(Focus Group 2)

Alison informed the group of her belief that the hospice provided respite care. While some hospices offer this for their patients, the local hospice in this area does not offer this service. It may be that Alison's family thought they received a form of respite when their family

member was admitted as an inpatient for support with a different need, possibly symptom control and pain management. For Alison, this was an important part of the care the hospice gave her family. It indicates however that while the hospice does not actively offer respite care, patients and families may feel they are receiving this service when a patient is admitted. The clarity of the labelling of services therefore may be an important issue for hospices and their local communities to address.

Personal experience was used to comment on some specific provision, particularly around family support:

> *'The care involves cooking, feeding, medicine, cleaning… They will talk to children, and they got counselling, you know, bereavement, grief kind of counselling for children as well as adults'* FG1- Brenda

> *'All the support that they gave, as my family were passing, support they actually gave to us on the end of the phone when I was in tears feeling like I just absolutely couldn't cope anymore, and that I needed extra help and they were there for us'* FG2- Bea

While some of these comments may not be accurate, for example the hospice doesn't provide cooking services (except for inpatients) the care and support provided for families was discussed by participants who had directly experienced this. Other care provisions mentioned included offering emotional and psychological support. Participants gave examples of playing games as one way that form of more holistic support could be offered within the hospice unit:

> *'It's just a stress relief, cos you're not sitting there on your own thinking "Oooohhh, I want to play a card game" or whatever, it's just a relief, and that's what Willen is. It's a relief. So you're not sitting there pondering and thinking "Ohh oh ohh", and that's what I associate with a hospice'* FG3 - Cliff

> *'I would expect a certain amount of distraction as well, if you, coming back to your point about running away from it, obviously not in a position to run directly, but take your mind off it, but maybe laying on games of scrabble, or concerts or whatever'*
>
> FG2- Alison

This distancing oneself from the reality of dying appears to be a common method of not just managing the reality of dying, but also to reduce that stigma attached to it (Goffman, 1963) It is also potentially necessary in order to provide a truly healing and therapeutic environment (Gesler, 1992). The purpose of therapeutic landscape is not necessarily solely to make someone 'healed' in the context of no longer being ill but is also concerned with the temporal psychological wellbeing.

This psychological and social support was, however, only mentioned in the context of the inpatient service within the hospice itself, indicating a lack of awareness that this could be provided within the community. There were no other specific forms of care or provision mentioned by the groups, but they did discuss who may access services which is discussed next.

8.2 The Inclusivity of Hospice Care

The next theme identified to what extent participants perceived palliative care delivery was inclusive. There was confusion about eligibility for care with regard to any diagnosed condition, as well as individuals' social, cultural, and socio-economic situations. This was demonstrated during the vignette exercise which explored different fictional characters who may have been supported by the hospice (see Chapter Five and Appendix 10). All the focus groups engaged positively with this activity and spent significant time discussing each fictional character. The responses indicated an assumption that hospice care was mainly for cancer, evidencing a similarity with the findings presented in the previous chapter. The following exchange in Focus Group 1 took place when presented with a fictional character described as having pancreatic cancer:

> Celia: When I think of a hospice I think of people with cancer to be honest
>
> Ed: Yeah I do as well
>
> Brenda: I do
>
> Angie: Yeah
>
> (Focus Group 1)

Other respondents associated hospice care with cancer because of their own experience:

> *'I remember hearing about it when I was a kid, and when my brother was suffering from cancer, many many years ago'* FG3- Dillon

The focus on cancer that was perceived by participants in this research, as shown in Dillon's response, is understandable when noting the prevalence of patients with cancer who use the local hospice, evidenced in the referrals data (see Chapter Two). So, while the participants' perceptions that hospices were mainly for cancer patients is actually correct for the local area, it isn't any criteria set by the hospice themselves for referral into their services.

The vignette activity also highlighted biases and prejudices among participants, and there was debate around whether specific patients from the vignettes were deserving of hospice care. This example from Focus Group 2 highlighted prejudices towards people who are incarcerated, as the fictional character was a prisoner with lung cancer:

> *'To be really mean shouldn't you say it's on his own head, he's the one who has broken the law and gone to prison, and then that's his lookout isn't it? To some extent, if he gets sick when he's in prison, well tough, he shouldn't have broken the law in the first place'* FG2- Cassie

There was a similar prejudicial response when discussing a fictional character identified as from a traveller community with stomach cancer:

> *'Well, yes you have to take things into consideration like their lifestyle, and how they live, and types of people they are, if you know anything about travelling people they are very, erm, they can be quite volatile, they are very outspoken, they are very, they can be very in-your-face, not everybody, but, they, they, do have a tendency to have their flair side of them, and you have to think about where they are going, in line with you have all these other very sick ill people…'* FG2- Alison

There were also prejudices demonstrated about people's cultural background and economic status. One vignette described a lady originally from Pakistan who had a diagnosis of multiple sclerosis:

'If she is from Pakistan, I mean if she has been born and got British citizenship here then the Pakistan is irrelevant, if she is an immigrant from Pakistan and an illegal one, you could say why should we treat her at all, she's got no legal right' FG2- Debbie

There was no challenge within the groups to any of the responses given that that expressed prejudice and racism towards some of the fictional characters. Whether that was because of a silent compliance with the opinions voiced, or a reluctance to challenge openly within a group environment, or another reason it is unclear.

Linking with the cancer focus discussed in this chapter, there was confusion around whether hospice care was specialist, or whether other providers were more able to deal with specific conditions. For example dementia and motor neurone disease (ALS) as described by these participants:

Willen is more sort of long term and end, end, end- of-life care rather than, taking on stuff like dementia. You might be able to provide a bit of help, but there would be people who specialise in dementia that have got actual training for it … you have to have special training to deal with people with dementia. You got to be able to deal with getting grabbed suddenly, and getting bruises, and getting knocked around' FG3- Dillon

'You got like, erm, people with ALS which is, you know, horrible, horrible death, but do they get, you know, do Willen take them in? Because I should imagine the care that's needed for anybody suffering from ALS is, more intense, than you know, no disrespect, but than anybody with cancer' FG1- Dora

This links with the presumed cancer specialism, but it also demonstrated that hospice care was perceived as less specialist with other conditions, and therefore less able, to manage non-cancer life-limiting conditions such as motor neurone disease. There was also confusion around whether all terminal conditions could be, or indeed even needed, any kind of support like hospice care. This demonstrates not just a lack of understanding around hospice and palliative care, but also a lack of understanding around specific medical conditions, their trajectories, and their care needs. For example, one focus group participant did not recognise that patients with heart failure could benefit from hospice care intervention:

> *'Heart failure…well it might be terminal but there must be thousands and thousands of people with bad hearts, but they don't go anywhere, they just go in the end, bless them'* FG1- Dora

This level of knowledge then could impact on inclusion as anyone referring patients needs to ensure the patient and their family is not only aware of the terminal nature of their condition, but also that hospice care can potentially meet the care needs for that specific condition. The general consensus by the end of the focus group sessions, however, despite what was said throughout the vignette activity, was that hospice care was inclusive and reflective of the Milton Keynes community:

> *'Willen is for everyone who is either there for like, their last legs not being, you know they are on their last legs, or they need like a helping hand, or they need someone just to sort of like, just look after them, just try and help them'* FG3- Brian

> *'If I'm honest I don't think Willen wouldn't turn anybody away in the grand scheme of things, they would do the best they can under the circumstances'* FG2- Bea

For any hospice care provider to be inclusive, the services provided need to be accessible to that wider population. This wider inclusivity of hospice care is the next theme that is discussed in this chapter

8.3 Accessibility of Hospice Care

Access to hospice care was a theme linked strongly with the inclusivity of hospice care. Confusion was vocalised regarding whether there was a referral process to get access to hospice care services. People's experiences clearly affected their understanding and participants were keen to share that knowledge with the rest of the group:

> *'The doctors don't give a damn, the GPs don't bother you know contacting, reaching out for help … they sent this erm, geriatric specialist out and when he was going, he said can you walk me out, and when we were in the corridor, he said do you know your mum has cancer and I said no. I knew she'd been ill, and I'd been up and down the health visitors, but she was offered nothing. Absolutely nothing. She got no visit from nobody'* FG1- Brenda

Brenda had quite a negative experience with her family member and reflecting in the group she was upset that they were not offered any support for end-of-life care by her GP. This response indicated again how participants perceived referrals should come from a health professional. Her anger was directed at the fact the health professionals hadn't offered any support such as hospice care, even though she could have contacted the hospice direct herself, if she had known. It also highlighted how, in her opinion, she did not get any support from anyone. Of course, hospices are not the only local providers who can provide care and support for dying patients and their families. The move towards more community-based care with charities, communities, families, and professionals collaborating together would mean for Brenda, that her mother could have received visits from anyone, not necessarily a hospice nurse.

All three groups believed there must be some system for referral, and the general view was that would be undertaken by health professionals, but no one knew the process. The lack of knowledge and certainty around how people can access hospice care encouraged discussions between participants:

> *Cliff:* *How do you get into Willen? I mean do you have to pay? Erm I would assume through the hospital or council?*

> Aaron: *A panel possibly?*
>
> Emile: *A panel of?*
>
> Cliff: *No*
>
> Interviewer: *Who would be on the panel?*
>
> Aaron: *Well, I don't know*

<div align="right">(Focus Group 3)</div>

As seen in this example from Focus Group 3, there were thoughts about whether it was a free or paid service, and if a panel would assess potential patients for their eligibility, but no-one had any real clear understanding of accessing hospice care. The first principle of Sallnow and Paul's Spectrum of Community Engagement (2015) is to inform communities. Clearly informing the public about how people can currently access care is vital in order to break down common misperceptions of access and improve inclusivity. There was also the assumption that referral for hospice care meant attending the actual hospice building (which will be discussed further in the next theme 'place') and that influenced how participants believed someone may access care:

> *'I think they would have to weigh up also the practical provision of beds in the hospice and the hospital at the time someone was in need, and it might be better for them to go into the hospital if they haven't got a bed for 2 weeks in the hospice or something'* FG2- Debbie

Debbie was concerned about bed provision indicating that accessing hospice care wasn't just about attending the hospice building, but also being an inpatient and staying at the hospice to receive care. The belief that access to hospice care was dependent on whether there was a bed available would indicate firstly a lack of knowledge on what services can be provided, but also another key aspect relating to accessibility. If a patient feels they can only get hospice care by having a bed in the hospice, they may be reluctant to accept if they are unable or do not want to stay at the hospice. They may have caring responsibilities at home with children or pets, have a fear of staying in the hospice, may find actually getting to the hospice difficult

because of transport issues, or some other reason which would make them reluctant to attend the inpatient unit. Personal experience of accessing hospice care was recalled by some of the participants. Angie explained how her sister accessed hospice care:

'My sister was told she would never leave the hospital, cos she got diagnosed in the hospital, and then she had her first lot of chemo, and it started to work and then they were like, ok, erm, they transferred her straight to Willen hospice' FG1- Angie

This experience also relates to the inpatient services so reinforced the groups' belief that inpatient services defined hospice care and was strongly linked to the physical building. This concept of hospice care being inextricably linked to a place is discussed in the next theme.

8.4 Place

The purpose of the focus groups was to encourage discussion around hospice care; however, the participants often turned the focus onto the actual hospice itself; its physical location and building. The participants frequently talked about 'the hospice' rather than 'hospice care' even when directly asked about the care provision, who is eligible and how people access care. Participants consciously spoke about the physical location of the hospice locally, and the building itself, irrespective of whether they had visited it, and assigned various topophilic and topophobic perceptions to that setting. One analogy used was comparing it to a care home for older people:

'It's to do with care and comfort, rather than emergency surgery or something, not a hospital exactly, but more like an old people's home' FG2 – Cassie

'In some ways I'd see it as a bit like an old folks' care home, sort of similar, with some similar issues. It's not the same thing, but I would expect a certain number of lounges, comfortable seats, you know, nice beds, areas where families can go' FG2 - Alison

This idea of likening a hospice to a residential care home for older people could be seen as associating older people with hospices, and the concept of receiving residential care as is seen in local communities in care homes. Such a belief may impact on whether a younger person would consider it a possible option for their care needs, irrespective of whether they needed to attend the hospice itself or not, because they would not necessarily associate themselves with the residential care settings, they may be familiar with locally. The concept of it being a place to stay, and homely was prominent in all three groups:

> *'I don't actually know about the hospice…. I know it's sort of like, you know what I mean, it's a home, it's trying to you know, help you… I haven't experienced it myself, but that's what, what I know, it's like a, a house'* FG3- Brian

This was also seen in Focus Group 1 who discussed their perception of the hospice as a physical place for older people, and mention homely artefacts such as carpets and bedspreads, identifying it as separate to a medical environment like the hospital:

Brenda-	*It's a bit more homely than a hospital, for me*
Angie-	*It's an old people's home, it's still got that almost quite, sterile smell and feel to it*
Dora-	*Yeah*
Ed-	*That's how I see it*
Brenda-	*But it has nice carpets and bedspreads, you know*
Celia-	*I imagine it to be like that too*

(Focus Group 1)

When asked about the care provided, groups still focused on the physical setting and the inpatient service:

Angie-	I suppose they are all different. I think she said they've only got 15 beds.
Ed-	Is that all?
Angie-	Yes.
Ed-	Thought it was bigger than that
Interviewer-	Why do you think the hospice would have more than 15 beds?
Ed-	It just, it seems like quite a big thing, like erm, it's the name in Milton Keynes that comes up and you think about hospice care, and there's a lot of charity work that's done for them and you see lots of fun runs and those kind of things, erm, and they've got a number of charity shops, and that kind of thing so I thought it was a much bigger operation than that.

(Focus Group 1)

Focus Group 1 appeared to believe the amount of care provided was directly linked to how many beds were available at the hospice. The surprise at the number of beds may be connected to their perceptions of the amount of work the hospice delivers locally, and the participants found it hard to correlate that much work with the small number of beds. This strongly evidences their belief of hospice care being primarily, if not solely, concerned with what is provided within the hospice setting for patients who would be resident there.

When conducting the vignette exercise with the focus groups, all three defaulted to considering whether the characters would be admitted as inpatients to the hospice, rather than thinking about whether the hospice could provide other forms of care. This included participants who knew or had discussed earlier in the session the different services such as day care, family support or care at home. For example, when presented with characters with cancer, they only considered admittance to the inpatient unit:

'I would have thought that this was a clear case of someone who should go into a hospice' FG2 – Cassie

'She could be accommodated at Willen if they've got a bed for her' FG3 - Dillon

There was more discussion around the care for the vignette character who was a prisoner with lung cancer, which defaulted to consideration of the inpatient service at the hospice building, as shown in this interaction in Focus Group 3:

Cliff-   *I think he's, he deserves to be in Willen*

Aaron-   *Yeah*

Dillon-   *But then again with prison services, and the general public, it probably wouldn't be allowed, because he's meant to be locked up, they will have prison nurses*

Cliff-   *They won't have prisoners at the hospice*

Aaron-   *They don't have the security to keep someone like that*

Brian-   *Yeah that's the thing yeah if he's a lifer, he's a threat to society*

Dillon-   *I think prison health services would keep that under wraps*

Cliff-   *No, Willen is more of a home, and prison is a prison*

Emile-   *Bars on the windows, and guards and that*

(Focus Group 3)

Despite being informed that all the characters were recognised as in the last year of life, the participants still perceived the label of prisoner to mean someone who was dangerous, and that extra security would be required to admit the person as an inpatient in the hospice. The home environment of the hospice was perceived not to be appropriate because of his status as a convicted offender. Even so, the group still defaulted to only considering inpatient services within the hospice as the only way for the character to receive hospice care, and not for any services and support to be given to the patient within the prison, or for the prison staff to be supported by the hospice to deliver palliative care. The stigma that was attached to the fictional character, evidences how difficult it may be for this population to access care,

if perceptions within society are that they are not deserving, or not able to access it because of their status. So, while there may be stigma around hospice care with the public perception of this being a service for people who are dying, other stigmas may be present around patients which could affect their inclusion and access to other forms of care.

For non-cancer conditions, there was again an emphasis on place. In this exchange between Focus Group 1 participants there was discussion about going into a hospice or going into a care home for a person with dementia:

Brenda-   *They don't go in a hospice they go in a care home*

Dora-   *They will have completely different needs*

Interviewer- *Do you feel that the hospice can't provide any care for people with dementia then?*

Dora-   *Well I don't know, but I'm thinking, no.*

Brenda-   *Yeah I don't think hospice is right, because I think like, you've got to be specially trained in that and that it's better to have, for people with dementia to go somewhere where people will understand them, their needs and help support the family*

(Focus Group 1)

This focus and assumption of hospice care being provided within the hospice environment therefore created discussion that some people may not be appropriate to receive hospice care within the physical hospice setting because of their condition, or their personal situation. It was of interest that every group defaulted to this view when presented with the fictional characters, and didn't contemplate any other options, even though no-one had any direct experience to corroborate this view. They didn't consider that the hospice could provide support elsewhere, even in a prison or care home, or that it could support the staff in those environments. Instead, this assumption that inpatient care was the only form of care was

generally agreed by all the participants, which they linked to the reputation and ethos of the charity which is discussed next.

8.5 Values and Ethos:

Another key finding was that the community members gave considerable thought to the hospice's values and ethos. The participants were particularly vocal about how they believed hospice care provided a high quality and personalised service which was part of the hospice's working ethos:

> *'From my aspect what they do is probably a higher standard than probably a lot of hospices currently, probably across the UK. It would be interesting to see where it ranks'* FG2- Debbie

> *'Well the physical environment is like as well, if you went in and it felt quite clinical and hospitally, I mean I personally would be a bit like, I don't want to be somewhere that's lacking in, I don't know, anything personal'* FG1 - Dora

While Debbie did not have any experience of other hospices, she had such a high regard for the local hospice she believed it must provide a better service than other hospices in the country, demonstrating how well it was thought of locally. This could be perceived as a form of loyalty to the local hospice, and a true topophilia of the care setting and the hospice organisation. Dora focused on the physical space of hospice care. She expressed her belief that hospices provided a much more personalised care environment, in contrast to a clinical hospital setting. This is certainly an aspect of care that hospices do strive to achieve and contributes to the high regard they have with local populations. Indeed, a commonality throughout all the focus groups was a high regard for the local provider of hospice care. It had a very positive image within the community, focused again on the physicality of the setting and the organisation, rather than the actual care delivered:

> *'Nothing is better than that place, literally'* FG1- Angie

'Erm, I do see it as having a good reputation and my personal experience has been charity shops and charity events' FG2- Cassie

Cassie acknowledged she had no direct experience of hospice care, and her only contact with the charity was through fundraising activities, but she was still very positive about the hospice and its care provision. There was also the strong presence the hospice had locally, which was often expressed alongside comments connected to fundraising and the need for extra funding:

'It's the name in Milton Keynes that comes up and you think about hospice care, and there's a lot of charity work that's done for them and you see lots of fun runs and those kinds of things, erm, and they've got a number of charity shops' FG1- Ed

'They are quite good at promoting themselves, like they often at sports events, races, things like that, they've got quite a strong presence, so I'd say they are both well regarded in terms of their marketing effectively and in terms of the experience that local people have of them in general' FG2- Bea

It is of note that participants perceived that the fundraising activities were also promoting the hospice. Clearly it had made the brand of the hospice very well known locally, however the events that were discussed were all connected to raising funds rather than raising awareness of hospice care and the different services the hospice provides or publicising how people access hospice care. Despite this, the positivity and love of the hospice was highly prevalent throughout all the discussions.

There was a particular divergence in opinion with Focus Group 3 which comprised of people from lower socio-economic status who were all experiencing homelessness. All of this groups' participants were less aware of the hospice compared to the other focus group members, and they discussed that this needed to be addressed:

> *'I don't even know much about them, I really don't but I've done things for them. I haven't picked up any literature or been to a barber shop or supermarket and picked up a leaflet about Willen Hospice. I think they are missing out a lot, not many people know, I mean, some of us don't even know what Willen hospice is'* FG3- Brian

> *'I don't think their services are reaching everybody and I don't think the awareness is there, and they need to'* FG3- Dillon

> *'It needs more publicity, Willen needs to put itself out there a bit more'* FG3- Brian

Participants expressed a desire to be more involved and support hospice fundraising, as well as to find out more about hospice care services and support:

> *'We got a guy here who can fundraise. You can send him out there with a quid and he'll come back with £4 in his pocket! (Laughs) Just send him up the street with a Willen badge on'* FG3-Dillon

The focus group of men experiencing homelessness seemed to be most aware of their lack of knowledge, but were also enthusiastic about wanting to improve this, and have more involvement with the hospice, particularly with fundraising. Homelessness can create a segregation away from society, and a disconnect with local communities, which may indicate why this particular focus group expressed a keener desire to get actively involved than the other two groups.

The idea of the hospice needing to promote its care to the local population was noted by Focus Group 1 in relation to the hospice raising more funds:

> Angie-   We're not any the wiser about Willen

> Celia-   It's known so well in Milton Keynes

> *Dora-*   *They put themselves out there to get money off you, but they don't say, well now and again I think I've seen come to our open day, we're selling stuff. Yeah people do things, but they don't tell the public what it is, what do they expect us to know, or imagine what it is like? I don't know*

> *Ed-*   *I think given the amount of fundraising they do I think it would probably be beneficial to them if the community had a greater empathy*

> *Celia-*   *Yeah like for example there are two people here have been in Willen hospice because of cancer, and so people who personally affected by cancer would be touched by those kinds of stories and that would therefore drive the publicity and drive the fundraising…*

> *Dora -*   *I've never gone out to find out, I'm sure they've got a Twitter page and website which details exactly what kind of care they do, but you know, I've never looked for it*   (Focus Group 1)

In this extract of the discussion, Angie felt the group did not have much knowledge about hospice care, Dora expressed how she perceived the hospice doesn't really promote its activities, but also that she hadn't ever thought about finding out about the work of hospices. Ed agreed that maybe people should have more knowledge so they can empathise more when the charity is fundraising, and Cassie raised the suggestion of using people's real-life stories of accessing hospice care to raise awareness. This suggests that there may be a real need and desire locally for people to know more about hospice care, beyond the constant appeals for funding, and for greater engagement between the hospice and its communities. As discussed earlier in Chapter Three, this is already happening in other areas of the UK where public health is being promoted and engagement is on a wider societal scale. This appears to be reflective of the direction of current policy and practice. The participants for this study expressed a sense of positivity about becoming more involved and collaborating with their hospice provider.

Focus Group 2 was also focused on the financial and fundraising aspects of hospice care, and discussed how that is part of the local knowledge of the hospice:

'It's lovely but it's really, hard hitting how much money they need, and they don't get funds from the government it's all seems to be coming from all these charity things that they have to do, to raise the money... I can't speak highly enough of them; I just wish they got more funding from somewhere. I know that I do my bit, I do my lottery and all the other bits and bobs, and charity things, I know that I do that, but I do wish that there was a magic wand somewhere that would say Kerching! You know you don't need to fundraise quite as much anymore ladies, there you go' FG2- Bea

Bea's comment shows how the hospice's need for funding has impacted on her views of hospice care. Her lack of knowledge around the funding streams for hospice care has made her perception to be that all funding has to be provided through the local communities and fundraising. It was not clear from the discussions where her perception was derived from, but it appeared to influence and enhance the positive regard towards the hospice and their work, possibly due to a positivity around the charitable sector generally within the UK. Bea also implied that fundraising needs to occur, and genderises the fundraising activities possibly due to her experience of mainly women as either paid staff or volunteers at the hospice, or who oversee and manage fundraising activities locally. While again it was not clear why Bea had these views it is interesting to note how the charity status and ethos had impacted on her, and other participants' positive assumptions about the hospice. The high regard for the local hospice was clearly seen from many of the responses, as well as a strong connection with caring for people who are actively dying, which is discussed as the final theme of this chapter.

8.6 Finality

The last theme identified concerned the finality of hospice care. As discussed earlier in this chapter, this was another prominent topic often associated with in-patient care. The focus on the physical location was important for the previous theme of place, but it was also linked to several discussions about the finality of hospice care as occurring at a place and time where death occurs, often referred to as a place where you do not leave:

'You go there you are not coming back. I've seen the hospice. That's how I understood it. No coming back out. It could be a year, it could a day, but you go in there, you're not coming out' FG3- Dillon

'You don't really think of people coming back out do you?' FG2- Eric

For many they associated the hospice with death:

'I think of death, that's what I think of about the hospice' FG1- Celia

'I think that people, like you said, you know at end of life go in and they are there to die so, like once you are in a hospice I thought you don't normally come out' FG2- Debbie

'I thought it was a place to die' FG1- Ed

From the discussion, there was a general consensus that the hospice building was a place you did not leave. It was seen as a definite sign of the finality of life, a place to go and die. The groups used this language of 'not coming out' as a euphemism for death itself, suggesting that the person entering dies within the hospice, but without using the direct terminology of death. This expression revealed a fear of the hospice itself, and because of this connection, of hospice care. This is a stark contrast to the love of hospice care described in the previous section. Perceiving hospice care as synonymous with the hospice as a place to die could undoubtably impact on people's willingness to consider hospice care as an option for themselves, for their families, and those who could refer patients for hospice support. Connecting hospice care with death and dying can also negate a lot of the support and care that is provided for patients given in the months, possibly even years, preceding the very final stage of life. There was overall agreement across all three groups that hospice care was for people at the very end of life – days or maybe weeks:

So she (relative) *went there for like the last two weeks of her life, so I think from that, that's where my understanding of a hospice was, so I thought it was more terminally ill people rather than regular treatments, and like I also thought that when you are in there, you'd be staying in there'* FG2- Cassie

'I think you're really got to be extremely ill and perhaps quite near the end before you go into the hospice' FG1- Celia

The participants believed the time when patients were accepted into hospice care was the point of being very close to death and so would be requiring inpatient services for that final stage, clarifying why they felt it was the place of death. Even those who had experience of hospice care, still defaulted to this view of hospice care being for the very end.

'Hospice care is that end of life, last few weeks, making you as comfortable as possible' FG1- Angie

'It's helping people to live out their last moments of life' FG3- Brian

Brian's comment was telling as hospice care is certainly about helping people to live out their final moments of life. Of course, helping people live their life can be achieved in many different ways and is not necessarily restricted to within the confines of the hospice building, or only within their last few days (Donmez and Johnston, 2020).

8.7 Summary

This chapter presented the findings from three focus groups with members of the general public to ascertain their views on local hospice care provision. There was a tangible focus on the inpatient services provided by the hospice within their building, and hospice care was often discussed alongside the physical hospice setting itself. That attachment to place was seen as both a love and fear of the physical setting; a love of the delivery of that care, the homeliness of the hospice and the ethos of the hospice organisation, but also a fear of it being a final destination where people enter but do not leave. Personal experiences shaped some participants' understanding, and those without any direct experience were open in expressing their uncertainty about the different types of care and support those hospices may provide, and how it would be accessed. There was considerable discussion on the inclusivity of care

and who may be eligible, where participants did not demonstrate any clear understanding of who hospice is for, besides a focus on those with cancer, and at the end of life, that is the last few days of life. The groups did, however, express consistent views on the ethos and values of hospice care, particularly in relation to the local provider and its need for fundraising to provide the services locally. There was a genuine positive reaction to the hospice in that there was a perception that there was very little improvement that could be made to the service.

It was interesting that even though there were some participants who had direct experience of hospice care and could relate to other services and support, the groups still defaulted back to this perception of hospice care being within a building, as an inpatient, at the very end of life. It was also surprising to hear the prejudicial comments from some participants in relation to who is eligible for care and should access it. While the assumption of hospice care being a cancer specialism could be predicted, certainly based on the recent data of hospice patients using the service, the reluctance to agree hospice care could be for prisoners, refugees or people from a traveller community was unexpected. Some of these findings correlate with the results of the interviews with patients, which are the focus of the final findings chapter presented next.

9. Findings: Perspectives of the Patient

This chapter focuses on the perspectives of the patient, through the data collected in 1:1 interviews with patients in the last year of expected life within the Milton Keynes community. The patients were referred by health care staff who knew their prognosis and mental health, this ensured they were able to participate. Eight patients in total were interviewed. Three of those were currently accessing hospice care, one had been referred but was awaiting contact with hospice staff. The other four were not known by the hospice. When quoted, this difference between being a hospice patient, or not known to the hospice is identified.

Each interview was in total over an hour in duration, and so there was considerable data collected from the participants. Therefore, this was the main source for this research, which is reflected in the breadth of findings reflected in this chapter. Similar to the other data sources, the interviews were analysed thematically which resulted in the following themes being identified:

- Provision and Need
- Ethos and Culture
- Finality
- Access and Inclusion

These themes are presented in turn in this chapter. The first theme presented from the data is that of identifying the types of provision participants either believed defined hospice care or was care they thought may be required at that end stage of life.

9.1 Theme of Provision and Need

Two aspects of provision and need were identified in the data. Firstly, there was the provision that the participants believed was, or should be provided by hospice care. Secondly there were the needs they thought a dying person would require themselves. While they did not always perceive those personal needs as a part of hospice care provision, they are included here as by definition they are the needs of a patient at end of life, and so may well fall under the holistic umbrella of hospice care, even if the patients were unaware of this. Three sub-

themes of provision were noted through the interviews, and these will be discussed in this section:

- Social and Psychological Support
- Family Support
- Practical and Medical Aspects of Hospice Care

9.1.1 Social and Psychological Support

Social and psychological support was a dominant sub-theme for most of the participants, particularly those who were engaging with hospice care. While they may not have expressly labelled it as social and psychological support, they talked considerably about the friendly and warm social atmosphere that they experienced at the hospice, and how the expertise of the staff enabled them to help cope psychologically with their prognosis. When questioned about types of care and needs of patients at the end of life, participants discussed social support, for example, assisting with social activities and inclusion with others. Care was perceived in a practical sense through the provision of resources such as the day centre, and access to activities such as the walking group, but also by indirectly offering social support through conversation and facilitating engagement in mutual social events. This was in contrast to social care, which was seen as supporting practical needs within the home. The need to support patients with their socialisation and inclusion was noted by Cicely Saunders several decades earlier in her original concept of hospice care and 'total pain'.

Having social support was commented on in all interviews and it was very clear that this was important to all the participants. For those accessing hospice care, it was most associated within the day centre setting, referred to as the wellbeing centre:

'It's just been the best thing, I really look forward to coming… everyone here has so much empathy, erm, but not in a condescending way, they really do genuinely say "Hello Barbara, how are you?" give you a hug, give you a kiss, it's just wonderful and we are all in the same boat, erm, which is nice, because you can't see cancer, can't see how people have suffered' (Barbara, hospice user)

The key aspects of social support identified were those around feeling acknowledged, included and valued, as well as having physical contact with others. Barbara noted this contact was with other patients as well as the staff and included volunteers who organised the wellbeing centre sessions. Social support also offered opportunities 'to be' and 'to do', with the day centre environment as an opportunity to be social, meet others and give a sense of purpose to life through being active.

Clive also noted the positivity and friendliness shown by people smiling, when he attended the day hospice setting:

> '*When I go to the hospice, I see smiles*' (Clive, hospice user)

Clive also expressed how the hospice was impacting positively on himself and the other patients he interacted with, and how everyone appeared happy at the hospice, irrespective of the collective understanding of why they were there. All of these responses were positive and showed an affinity and love of hospice care, that is comparable to the topophilia described by Tuan (1974) and Gesler (1998). Here, this love was attributed not only to the geographical space, but also the organisation and the care that was perceived to be delivered, such as that supporting psychological and social needs.

Similar to the participants who were accessing hospice care, those not known to the hospice also discussed in detail how their social support needs were met. This included interacting with others, even at a distance via the telephone, such as George whose family lived considerable distance away but were still close and supporting him, and Helen who had a supportive network of friends:

> '*I think the main thing in life when you are not well is to have the right support at home, and luckily, I'm a lucky person because I've got that. I've got that, not only with my wife, my number 1, because I've got two daughters… so I'm lucky person I have, I've got good support. My sister, she is 84, she phones up nearly every day from Jamaica*' (George, not accessing hospice)

'Well if I want to, I can pick the phone up and I've got a couple of elderly friends you know and my sister and I have this (iPad), we ring each other once a week you know to have a chat' (Helen, not accessing hospice)

Helen had developed a strong support group of family and friends that she engaged with regularly to provide her social interaction which she found helpful as a means to share her experiences. The phone contact was offering a form of social support through contact with other people to avoid isolation and exclusion. Social support was mentioned extensively in the interviews with patients not receiving hospice care; they identified it as a need, which was mainly supported by family and friends, either living with them, or they accessed through telephone calls or meeting outside of the home. They valued this interaction and noted that it helped them to have someone to talk to. When asked, the participants who were not receiving hospice care failed to identify this provision as potentially part of hospice care, but did identify it as something they needed, demonstrating a possible misperception about whether hospice care can include this more holistic support for social and psychological needs.

The main strategy for supporting emotional and psychological needs was identified by all participants as talking to others including other patients, family, and professionals, highlighting a focus on non-medical and non-clinical care and interventions, similar to meeting their social needs, but with more focus on the talking and sharing aspects of interaction with people. Several participants mentioned their need to talk about their feelings and difficulties. As Daisy was a hospice patient, she used the staff and volunteers at the hospice for this provision:

'The nurses, they sit there and talk, whereas the nurse in the hospital hasn't got the time, erm, and that's nice, and if you are worried about something, you can ask and somebody will come and sit with you, or pop into a room, and you can talk things through with them' (Daisy, hospice user)

Daisy expressed how she valued the hospice nurses and noted the difference between their ability to provide this psychological and social support, in contrast to her experiences at the hospital. For the patients not accessing care such as Frances, this was provided by their friends and family:

'I have friends that I would talk to if I want to cry. I've friends that I would talk to if I just want to rant, and then I've got a friend who is like "Oh for God's sake get over it! It's only cancer!" when you need that kind of friend' (Frances, not accessing hospice)

The patients who were not accessing hospice care, like Frances, had identified their own individual networks of support. There needs to be a consideration though of patients who are not able to source their own network because they do not have close family relations or friendships with whom they can engage in those supportive conversations and interactions that can meet their social and psychological needs.

'Going to the wellbeing centre kept me interested because I wasn't doing anything, you know, and I felt lost not having the purpose to my day, and that was really, uh, really does make you miserable really not having that' (Daisy, hospice user)

Psychological support was particularly important due to the emotive and challenging situations that face people with a life limiting condition. As Daisy commented, her mental wellbeing was impacted when she didn't attend the day patient setting; she expressed feeling lost with no purpose, which caused negative feelings. Psychological support was also strongly linked to social support, in that many of the support systems to improve psychological wellbeing were centred around engagement and interaction with others, and for the participants there wasn't a clear difference between social and psychological care.

The psychological impact on dying patients and their family and friends has been identified as a key issue within holistic palliative care and was another of the main concepts noted by Cicely Saunders. The link between social interaction, social support, and communication improving wellbeing and mental health is apparent within hospice care (Lewis *et al.*, 2013) and was noted by several of the interview participants in this research.

For Barbara, the depression that she experienced and how it impacted on her life, was noticeable for her as a psychological need and was more challenging for her to manage than her medical and physical needs:

> *'I started to feel very depressed, alone…. And erm, life wasn't good… people don't see what goes on, you know, in your mind'* (Barbara, hospice user)

Barbara expressed later that she found those needs were met by her physically attending the hospice and engaging with others in a social environment and was very positive about the hospice and the care provided to her. As has been demonstrated in the data examples given here, the support received by the hospice, or perceived to be delivered by the hospice, to meet social and psychological needs was seen as a positive characteristic of hospice care. It showed the love of hospice care and an affection for the hospice care provider. It also demonstrated that this was perceived as the most important care need for patients at end of life. No stigma or negativity was expressed around having that care need, but rather participants willingly discussed how either the hospice, or their own support networks were meeting those needs. Family and friends were clearly then a key part of support needs of patients. How families support patients, and how families are supported themselves is the focus of the next section.

9.1.2 Support for Family

All participants mentioned their families as being one source of practical, social and psychological support for them. This enabled discussion during the interviews around the support that families and carers may require for themselves when caring for someone with a life-limiting condition. The difficulties faced by families and friends, particularly as a result of the psychological impact from caring for a person who is dying, are well documented (National Council for Palliative Care, 2014) and were a recurrent topic in the interviews. A range of experiences were described, and family support was something that participants perceived was important. All participants showed consideration of the needs of their families

and friends during their illness. For hospice users, it appeared there was a lot of support available should it be required, however not everyone expressed a need for it:

> *'I see a lot of counselling, when we see the beautiful garden where you got like benches where people can sit outside, and I see them with carers out there, and they are looking after them, and er, wonderful opportunities for people to come and visit, family members, and they can er, I see them helping family members, handle the grief and anguish, I can see that'* (Clive, hospice user)

Clive disassociated himself from the family support delivered by hospice care staff but acknowledged the value of it for other patients and their families. This could be because his family were not local and so were not able to access the local hospice where Clive was registered as a patient. For patients not accessing the hospice, sourcing support for families was shown to sometimes come from other professional sources. Emma was receiving support for her family through the specialist health care team which was related to her condition:

> *'We all sat down and we had this meeting, and erm, they spelt it out for the girls, didn't they? And they said, you know, and if any of you want to come and talk to us, if any of you want to come and see us, you can, we are here for you all, and they've been fantastic like that'* (Emma, not accessing hospice)

Emma found this extremely helpful for her family and confirmed in her mind that her specialist health care team could meet all her palliative care needs without requiring any hospice care provision. However, it was also apparent that for some patients accessing support for families was extremely difficult. Frances emotively expressed the lack of support she had been able to find for her family during her deterioration, and between her three-monthly hospital appointments:

> *Frances:*   *I feel sorry for my husband because he is really on edge as well, because he knows that every three months, our lives could change dramatically*
>
> *Interviewer:*   *So what kind of, does he get any support?*

> *Frances:*   *No… no…. No support, and nothing has ever been offered… So, he's never been offered support from anybody.*
>
>   (Frances, not accessing hospice)

Frances also acknowledged the difficulties her family had with her prognosis and the lack of support received to manage this. She reflected how this impacted on her own mental health:

> *'I am actually on antidepressants, now, erm, because as I said I went through quite a bad period where I just didn't want to be here anymore, erm, so that's helped me, but my husband has turned to exercise because that's his way of dealing with it, erm, my son talks to me and my mum and dad, and in fact I think if anyone is taking it really badly, it would be my mum and dad….'* (Frances, not accessing hospice)

Three different experiences were expressed here; Clive, while not needing this support for his own family, is very aware of what the hospice is offering to others and how it benefits other hospice patients. Emma was not accessing hospice care but received support through her specialist health care team which she believed met her family's needs; thus identifying a palliative care need that was provided for outside of the hospice. Frances, who was not known to the hospice, was experiencing a difficult situation within her family, and not receiving any support. These three different local patient experiences provide a sobering and thought-provoking concern regarding how different these three patient experiences were, all within the same local population with the same services.

Other forms of provision were discussed, but these were far less dominant in the conversations than family, and social and psychological support. Participants recalled specific, practical examples of care such as in-patient services, respite, and home-based care. These findings are presented in the next sub-theme in this section.

9.1.3 Practical and Medical Aspects of Hospice Care

The practical aspects of hospice care were strongly associated with the place where care was provided. This was primarily the hospice building for the inpatient services and respite care. Less discussed was the use of people's homes as a place of care for hospice at home services. The idea of the hospice being a physical place of care was apparent in the responses during the interviews. The data analysis showed participants viewed this physical location as generally providing either respite care (even though in practice they do not directly offer this), or care for the final few hours or days of life (a concept that will be discussed further in the theme of finality later in this chapter). Alan recalled what he considered to be respite care provision for a friend:

> *'I mean because sometimes when you go to Willen, I mean I've been there to see people, and err, ok to start off with, they're not too bad, they've come out after a week or a fortnight, and they've been back home, and then they've been back again, and you can see over the course of time, how things deteriorate, and you think to yourself, hmm, not so good as you were last week'* (Alan, not accessing hospice)

Seeing his friend's condition worsen had reinforced to Alan that hospice care was for people who he considered were 'more in need' than himself. This was seen in his consideration of how his friend declined, and he confirmed his view later in the interview, when asked about hospice care:

> *'Well yes I think it's for people who are shall we say, wanting more care than I do, i.e. they want to have to be dressed, have to be washed, have to be looked after, sometimes have to be fed'* (Alan, not accessing hospice)

As he was able to manage practically at home, he did not think hospice care was necessary or appropriate at that point in time, despite being within the last year of expected life, because he was thinking solely about the practical care and needing to be 'looked after'.

This focus on hospice care being for respite or the final days of life also provoked an unwillingness in participants to consider the aspect of inpatient hospice care for themselves

as they associated the final days of life with receiving hospice care through the inpatient service. They preferred to distance themselves from that as an option, citing reasons such as they did not need any form of respite or social support, or they were just not ill enough. This demonstrates a topophobia of the hospice building as it was perceived to be only for inpatient care. The stigma they associated with that inpatient care was prevalent across the participants, even though they had little understanding of the service. Barbara was very aware of the presence of in-patients currently at the hospice, but acknowledged she knew very little about why they were there and what their care needs were.

> Barbara: Do they have fun? Are they well enough to have fun?
>
> Interviewer: Go and ask?
>
> Barbara: I think that would be a good idea, it's like a forbidden place, it is
>
> (Barbara, hospice user)

She wanted to know more about what happened there but hadn't ever thought about visiting that part of the hospice. Barbara had only attended the day hospice setting in one part of the hospice building and perceived the inpatient floor as somewhere she couldn't or didn't want to go. The implied segregation of day patients and in-patients is a challenge then for hospices to address as often these are two distinct separate areas of a hospice building, and this is a practical reality for the local hospice in this research. It may be something that needs to be changed in order to break down the myths around in-patient services that cause this fear and disassociation in patients, including patients already receiving hospice care provision. The physical segregation appears to confirm for Barbara that sense of difference between herself and the inpatients, creating a sense of othering, distancing and a tangible fear of the hospice space. This topophobia is discussed in more detail later in this chapter.

Less acknowledgement was given to services outside of the hospice building, such as care within the community. Care at home was noted by four of the participants, even though it is the main work of hospices within the UK (Hospice UK, 2016). Knowledge about this provision was given only in relation to previous personal experience or being informed of this possibility while using the hospice services themselves. Clive discussed this in his interview and

acknowledged he was not aware of this provision until he was accessing hospice care for his own needs:

> *'There's more people serviced external to the hospice, not serviced that's a bad word, but er, more cared for at home than what are cared for in the hospice, that's something I've learnt. I didn't know that'* (Clive, hospice user)

This may be concerning for hospice care providers, as one of the main barriers to accepting hospice care, as expressed by some of the participants in this research, could be the assumption that care is provided only within the physical building. This could deter people who do not wish to accept a referral because of its association with dying, or for cultural reasons, or if they cannot physically travel because of health, finances or lack of transportation. The focus on the physical location was more prominent in discussions than the actual practical and medical care that would take place either in the hospice itself, or in people's homes, and this is the next sub-theme that is presented.

Practical aspects of care such as medical provision were given less prominence during the interviews, and there was confusion as to what actually was undertaken by hospices in relation to these forms of care. Alan was very pragmatic in his understanding of care in that it concerned practical, physical, and medical needs, as mentioned earlier with his focus on being 'looked after'. Alan explained he was very capable at home, and this contributed to his belief that he did not need any support from the hospice. For Clive, who was known by the hospice, he was aware they provided medical care, but wasn't too sure what they provided. He had seen doctors at the hospice building and referred to this experience:

> *'The medical need, I know there is medical doctors available, aren't there?'*

> (Clive, hospice user)

Clive could not clarify any further than knowing there was medical expertise within the hospice. He didn't offer any examples of medical care he may have received, or other patients had discussed with him when he attended the day clinic, but he did know that the practical medical support was available if required. Some of the participants had experienced specific medical interventions from the local hospice, which they mentioned in their interviews. These

included physiotherapy, complementary therapies, and the lymphoedema clinic (managing problems with the lymphatic system such as swelling) which was a service available for anyone not just those identified as end of life. George expressed that his need for physiotherapy support was the reason for his referral for hospice care:

> *'I'm supposed to see somebody from Willen that will be maybe help me even more with the breathing… the physio from Willen'* (George, not accessing hospice)

This method of accessing hospice care because of a specific need was evidenced in other patients, such as Daisy who had been referred for lymphoedema care:

> *'At first it was just seeing the nurse in the lymphedema clinic and then she referred me on* [to the hospice]' (Daisy, accessing hospice)

Patients not accessing hospice care also believed that having a specific medical or practical need could result in hospice care being provided. Emma knew there were specific therapies provided by the hospice, but didn't comment on whether she believed she had any specific therapeutic or medical need:

> *'Sometimes you are going in the hospice for respite, sometimes you are going in just to, you know, because they've got therapies and stuff'* (Emma, not accessing hospice)

A person's experience of a service will undoubtedly influence how they understand and explain that service, and this was evidenced in this theme. Also, interviewee's experiences of services differed particularly between the hospice users and those not currently accessing hospice care. This included accessing what may be defined as palliative or hospice care provision from formal and informal sources outside of the hospice, for example Helen described her supportive son:

> *'You keep a list in your head of what I want him to do when he comes, getting things from upstairs is the problem; I have to wait for him to come… He comes up every day and I tell him it's not necessary'* (Helen, not accessing hospice)

This practical provision of hospice care was in contrast to the more abstract concepts of the ethos and culture around hospice provision, which is the next theme to be explored.

9.2 Theme of Ethos and Culture

A key aspect of this research was to ascertain people's understandings and perceptions of hospice care provision within the specified locality. As detailed in Chapter Two, the hospice is one of the most well-known charitable organisations within the area. Seven out of the eight patient participants had prior personal experience or a family member or friend who had received hospice care, and therefore were knowledgeable about the presence and work of the charity locally. Therefore, it was understandable that during the interview there were several comments on the hospice ethos, how it was regarded locally, and the culture of the perceived care that was given, which has created this identified theme of ethos and culture. After an initial analysis of the data the following sub-themes were noted:

- High Regard and Community Knowledge
- Fundraising and Advertising
- Homeliness and Expertise

9.2.1 High Regard and Community Knowledge

There was an overwhelming sense of high regard for the hospice, often with a reluctance to say anything that was not positive. Barbara was a hospice patient and demonstrated this reluctance in her responses to my question on how the hospice could improve:

> Interviewer: Is there anything in regard to the type of care they give, the things they actually do, is there any way they could improve in that, any changes or additions?
>
> Pause
>
> Barbara: I don't want to say any negatives

Interviewer: It's not being negative it's just, obviously there may be things that they are not doing, maybe because they haven't got the money or the staff or whatever, or it's never come across but you think if they also did this, or I know people would benefit from having that, or…

Pause

Interviewer: There might not be, but….

Barbara: I don't know, really, hmm

The high regard manifested in language used such as 'wonderful', 'lovely' and 'amazing', and was demonstrated by both hospice users and those not accessing the hospice. Daisy linked it to a comforting feeling about the hospice. She believed everyone knows of the hospice, so she didn't have to go into detail about the care she was receiving when talking to other people. She perceived that because of that underlying high regard for the hospice, it could put her friends and family at ease, to comfort them, that she was under hospice care:

> *'It's a place where everybody knows… If you say you are going to Willen, you don't have to explain where you are going. I think it's a comfort thing? For them? And somewhere that's going to look after me when I really need it… I think people have got a love for places like Willen, I really do… It's lovely and comfortable, and they're nice and warm, and there's all things going on'* (Daisy, hospice user)

Helen noted that she was very aware of the high regard for the hospice locally and that the local brand never appeared to have any negative connotations.

> *'I only hear good things about it. I don't hear anything bad about it'*
>
> (Helen, not accessing hospice)

While this may be thought of as an influential characteristic, certainly from a commercial or business sense, for potential future patients this still wasn't an influential factor in accepting hospice care. For example, Helen didn't want to consider hospice care for herself at this point in her life:

Helen:	They, the doctor, wanted me to go into Willen hospice, to keep an eye, you know a watch over me, but I didn't want that, I don't want to go… … She [the nurse] was asking, she was saying about the hospice, Willen hospice, all the forms to fill in and things
Interviewer:	Oh ok. Were you persuaded then? No?
Helen:	No, I don't want to go. I want to stay at home for as long as possible, there might be a time when I can't, I mean, do anything, and you know…

From the interview it was clear that while Helen was very positive and supportive of the hospice, to her being a hospice patient meant leaving her home to receive care at the hospice and she wasn't willing to accept that yet. It does bring into question whether the doctor and nurse mentioned in this extract explained to her the different kinds of support including the hospice at home service.

There was a real sense among participants that everyone 'knows' the hospice; that it was a well-known and loved organisation locally. There was a topophilia not just for the hospice environment, but the hospice as an organisation. This positivity impacted on people's willingness to discuss changes or improvements to the services currently provided. Clive perceived from his experience there were no negatives about the services they provide:

'I've only got positives; I have not experienced any negatives and I'm not going to say something to exaggerate a negative' (Clive, hospice user)

Even though this high regard was expressed in all eight participants' responses, there was still a lack of knowledge of what the hospice actually provided, suggesting within the community there is a love of the idea of the hospice, rather than anything tangible. Emma recalled this when reflecting on the local community:

*'They'll know about Willen Hospice, but they won't know **about** Willen Hospice'* (Emma, hospice user)

Emma was trying to explain how people have heard of the hospice and have a high regard for its care provision, but actually have very little understanding of what services and support are offered. This lack of knowledge about the care provided by the local hospice by some participants resonated with the other findings from the focus groups and questionnaires and prompted me as a researcher to consider why there was such uncertainty about hospice care provision, and also how this could be resolved. This could be connected to the advertising and fundraising strategies of the hospice, which is the sub-theme in the next section of this chapter.

9.2.2 Fundraising and Advertising

The link to promotion and fundraising was significant during the interviews as this was the primary image of the hospice that the participants recalled from their community and personal experience. They were highly aware of the promotional media that was displayed and promoted locally for raising funds. Everyone discussed this during the interviews, for example Frances and George had little knowledge of the support and care Willen Hospice could provide, but were knowledgeable about their fundraising activities:

> *'I know about the shops and a lot of fundraising. I've heard about the lottery. That's about it'* (George, not accessing hospice)

> *'I thought it was just somewhere that was really lovely, you raise funds for, and obviously I've done the midnight moo's* [sponsored walk at night] *and stuff like that raising money, yeah I know they light the Christmas, well the Willen light festival, and stuff like that, my erm, my best friend has a lot to do with fundraising for Willen Hospice'* (Frances, not accessing hospice)

In recalling the media and social presence of the hospice, the participants then reflected on this aspect and how the hospice appeared to focus primarily on the fundraising issue rather than raising awareness and knowledge about their work. Barbara perceived that more could, and should be done beyond the fundraising:

'I don't see anything on TV about Willen Hospice, you know we have our local news don't we, and they like, they have their fundraising things, and they have their little bit, but it's not like Macmillan, keeps coming up all the time…Macmillan this, Macmillan that… why don't they put something on our TV, our local news about Willen?' (Barbara, hospice user)

Emma commented that the hospice needed to do more to inform people about the support offered by the hospice as she believed the community was not aware of what was offered. Emma had been told about the hospice by her specialist nurse Nikki and suggested that knowledge needed to go beyond health professionals and be disseminated into the local community.

'Well I don't think people do know? I mean yeah doctors should know, but even via Facebook campaigning. Did you know we do this, we offer these services, if you've got an end of life or a serious illness we can do this for you, we can, offer you these, come in for our, if you've got an end-of-life illness, come in for the drop-in session. It shouldn't be that somebody like Nikki has to tell you because there's not always Nikki's around, so it should be Willen out there pushing it, and it's hard because Willen is funded purely by charity, all of these hospices are funded by charity, how many of them are NHS funded is zero, it's a joke' (Emma, not accessing hospice)

Emma thought she was privileged to have the support network of her specialist health care team but was aware that patients with other life limiting conditions may not have access to similar supportive networks. She expressed that it was difficult for hospices to possibly allocate money to this form of promotional and awareness raising because of their limited funds. This need to promote hospice care more to the wider public was seen as a positive step the hospice could take to build on their reputation and good standing locally as the experts of end-of-life care and providing homely care environments. This is the final sub-theme I address in this section on ethos and culture.

9.2.3 Homeliness and Expertise

Much of the high regard for the hospice came from an understanding of the hospice ethos particularly the homeliness of the physical hospice setting and feelings of 'comfort' for the patients and 'being comfortable'. The comfort can be seen as a form of love for the physical place, showing a topophilia among all the interviewees. This was either just a general awareness as expressed by Helen, or one gained from personal experience as Alan commented, when he recalled his friend receiving hospice care:

> *'It's just to make someone as comfortable as possible really. And erm, I don't really know much else'* (Helen, not accessing hospice)

> *'It's a matter of a caring sort of attitude… not to sort of be thrown against the wall and saying 'oh, he's not long on this earth we'll leave him where he is… for people to be made comfortable, basically'* (Alan, not accessing hospice)

As discussed, the participants didn't elaborate as to what that comfort or being comfortable meant in practical terms, or how comfort was delivered through hospice care. It was expressed more in a general sense that being comfortable was synonymous with that feeling of homeliness, being at home, relaxed and looked after.

The hospice was perceived as a place where staff were specialists in providing that homely, comfort care. Participants commented on the expertise of staff and how this influenced their experience and understanding of hospice care. Emma became aware of this when her dad was dying and discussed how she changed her mind about hospice provision and that, in her view, they could care for her dad better than she could:

> *'The hospital said "He needs to go to the hospice" and I was like "I don't want him to go to a hospice" and then they said "Just go and see it" and so we went over there, and actually we went "Yeah, this is a beautiful place" and it was, wasn't it, it was so lovely and we knew. I just, cos I thought I could do a better job at home, and the reality of it was, no way, no way, they were the best people for him"*

> (Emma, not accessing hospice)

The perception of hospice provision as specialist and something that lay people and families are unable to provide is important, as this again is perpetuating this perceived reality around hospice care providers being specialists and experts: a perception that the hospice may not even be aware of within their local communities. There was a strong belief that hospice care was specialist care for people with terminal conditions:

> Interviewer: So was it the hospital that suggested Willen hospice then?
>
> George: Yes, somebody to come out because they got people there with the expertise… with the expertise to help. My, well, my cancer people at the hospital, the NHS, they said there aint erm, you know if I get an infection, you know and stuff came, I should get in the hospital to treat it, but they can't, they can try and treat the infection, but there aint nothing they can do to make me any better than what I am.

George expressed this belief that the hospital could not provide the expertise for his cancer condition as it was now terminal, and therefore the hospice was the place which could offer the expertise he may need in the future when his condition deteriorates. This difference in hospice and hospital care was picked up by other participants. Emma strongly expressed her wishes not to go to the hospital for any future care needs. She did not see the hospital as a place where they understood end-of-life care.

> 'I wouldn't wanna go to the hospital, no, not the hospital. There's nothing they can do for me there, and they're not very, no, they're not erm, end-of-life specialists' (Emma, not accessing hospice)

However, George and Emma, despite being eligible for support and care from the hospice, believed it was not appropriate for them in their current situation. This is an interesting belief which may impact on whether people would choose to attend hospital when they have a life-limiting prognosis, and impact on the wider public stance of not wanting to die in hospital. The patients expressed this difference in terms of the expertise of hospice staff, in contrast to the hospital teams. That expertise was not just concerned with the medicalisation of care,

but the more holistic side of end-of-life care, such as the personal service as described by Daisy.

> *'I think the attitude to Willen is completely different to going into hospital. Very different. It would be lovely if the hospitals could somehow have the staff and the thing to work the way that Willen does with the almost individual attention'*
>
> (Daisy, hospice user)

Daisy noted the attitude of hospice staff, and how they could provide a more personal, individualised care for patients. She also demonstrated a perception that hospice care was a preferred option compared to the hospital particularly for older people, because of the culture of care:

> *'I think of people who are ill, or elderly people who are you know getting older and older, I think they would all want to, I don't know if they talk about it that way, but none of them want to go into hospital, none of them… it's not so much the individual care it's the lack of privacy, and the respect, lack of respect, lack of decency in hospitals… most people who are ill just want their dignity kept you know, which that's what they lose, whereas you don't lose that at Willen'* (Daisy, hospice user)

This perceived lack of respect, creating a reluctance among older people to access hospital care could also be a contributory factor for the larger numbers of older people accessing hospice care in this local region. Their perceptions of it being a more private, personal, dignified care that isn't provided within the hospital setting, could influence the acceptance of referrals for that demographic, and possibly even influence the referrers. Therefore, when looking at hospice care provision and who accesses it, it is clear then that a focus must also be made on other end-of-life care providers such as hospitals, nursing homes and clinics, and investigating why they do not have the same reputation and are not regarded as highly locally as hospice care provision, especially for older people.

The concept of acceptance and preference for hospice care among older people, but a reluctance in others who do not feel they are at that stage of their prognosis yet, links with

notions of stigma and societal responses to death and dying, which are also identified in the findings for the theme of finality, presented in the next section of this chapter.

9.3 Theme of Finality

Finality was often associated with hospice care provision throughout the data analysis. The Modern Hospice Movement originally conceived the hospice to be a place for people to receive care and support for a dignified death. This understanding has stayed within the culture of hospice care and was a prominent theme in this research. The participants were influenced by their own experiences of family and friends' deaths, as these were recalled extensively in each interview, as well as their own relationships with the hospice. The analysis enabled three sub-themes to be noted which will be addressed next:

- The End – A Place to Die
- The Fear of Hospice Care
- Stigmatisation of Hospice Care

9.3.1 The End - A Place to Die

All the patients interviewed had personal experience of someone dying at a hospice, except Barbara, and therefore it was natural that death and dying were the primary thoughts of those participants when trying to explain what hospice meant to them. Barbara also had this understanding of the hospice being a physical place where you go to die:

> *'A hospice is, I always thought it was where you came to die… a lot of people think you come here to die'* (Barbara, hospice user)

Opening up about their perceptions of the finality of hospice care, led to recollections of deaths they had experienced themselves, including family members, friends and neighbours. Some of these memories were hospice related, one example was Clive's recollection of a work colleague:

> *'The doctor came in, took some blood tests and what have you, and he had leukaemia. And then, er, within two weeks he was in a hospice, and this beautiful looking guy, he was er, just went…. He was gone, he was gone, just came, happen like that'* (Clive, hospice user)

Emma had been influenced by a death that occurred at a friend's home. She explained how this has influenced her decision to not die at home, because of her friend's response after the death:

> *'My friend had a little boy who died of neuroblastoma, and he died at home, he went home to die, and their house is like a mausoleum to him, and I don't want that, I don't want the kids to do that'* (Emma, not accessing hospice)

Frances had experienced two relatives dying in the hospice, and had decided she would prefer to be at home:

> *Frances:*   *Hospice… that's somewhere I go to die, like elephants go off somewhere to die. If someone said hospice care, I would think of my experience of it, with my aunt, and my friend's mum, they went in, literally, and then died a couple of days later.*
>
> *Interviewer:*   *So you see it as right at the end of that time then*
>
> *Frances:*   *Yeah like when you can't be looked after in your home anymore, then you would go into a hospice to die…. I mean personally I don't want to go into a hospice to die, I would rather die at home… as much as I can. You know if it came to it and I would have to go in there, it wouldn't be the end of the world (laughs)*
>
>   (Frances, not accessing hospice)

So while participants had a general consensus of the stigma around the hospice being perceived as a place to die, it wasn't necessarily where the patient wanted to die. Only two

participants actually discussed their own anticipated deaths in any greater detail beyond preferred place of death. George spoke about how he believed that dying may not be that traumatic for him:

> *'I realised in hospital, when I was unconscious, I mean I didn't know anything about it. It just happened. So if I didn't come back, it's because, it's not like, it's not like I was there and feeling dizzy and thinking "Oh well I'm not well". I was there and then next thing this nurse said, I just went (claps hands)'* (George, not accessing hospice)

Emma discussed her condition and its prognosis, expressing an acceptance of her anticipated death, and recalled her conversations with her doctor:

> *'She said "Are you aware of the end of life?" and I said "Yeah, it's gonna be shit, I'm very aware of it, but it is what it is, nothing we can do to change it, we'll deal with that when we get to that point"'* (Emma, not accessing hospice)

The difference in fear and acceptance of death was seen then between the participants in their responses during the interviews. They also expressed differing perceptions of a fear of hospice care due to its strong links with dying, which are shown next in the next subsection of this theme.

9.3.2 The Fear of Hospice Care

The fear of hospice care, and perceptions of dying and becoming a hospice patient, were divisive themes during the interviews. There were differences in the fear of hospice care between the different ages of participants, with the younger patients under 60 years of age expressing more fear than the older patients. Frances, who was 47, believed using any services from the hospice was accepting the label of 'dying'. In her view this was a common perception, and it created a fear to be associated with, or go to the hospice for any reason because of that label:

'I think most people are scared of Willen Hospice, and to be associated with anything to do with there, like, be it counselling, or lymphoedema clinic, because automatically if something has anything to do with Willen Hospice it's because they are dying' (Frances, not accessing hospice)

This fear and labelling of the hospice connection with death and dying created a reluctance among the younger patients to accept hospice care referrals. Barbara, who was 57, agreed there was this stigma of hospice care and its association with death. She acknowledged an irrational fear of potentially shortening her own life if she were to agree to hospice care:

'When I was asked if I'd like to come here [hospice] *I sort of thought, "Oh I don't know if I want to go to the hospice" and I didn't know if I was jinxing myself. It's really silly, you have this, these thoughts and you know, like "I hope I never have to come here because I'm really, really il;"'* (Barbara, hospice user)

Barbara knew her thoughts were 'silly' because she was already a hospice patient, but she was distancing herself from what she perceived to be hospice patients, that was the in-patients who were in a different part of the hospice building to the day centre she used. Barbara appears to suggest that her attendance at the hospice centre is for different reasons to being chronically ill. Emma, aged 49, was also reluctant to accept any referral to the hospice because of feeling she wasn't at the stage of life when hospice care would be needed, and due to its symbolism of death:

'So the Willen lady said, "Oh you can come and see me, come for tea on a Thursday" and I went "I ain't fucking dead yet! I ain't ready mate!" (laughs) and she said "I understand, we know about that" and I said "I'm not ready yet" and she said "When you gonna be ready?" and I said "I don't know"' (Emma, not accessing hospice)

For Emma, hospice care meant accepting death, rather than considering any forms of practical, social or psychological support for the weeks and months before the end-of-life phase of her prognosis. This reluctance and fear of hospice care was contrasted with a much

more accepting and positive view from the older participants. Daisy, 81, perceived that fear was actually only a temporary feeling connected more to their diagnosis rather than the hospice itself. As discussed earlier, she perceived hospice care to be a preferred option for older people, because of its association to comfort and care. This is noticeably different to the younger participants views of the hospice either 'jinxing' them into dying, or for being a place to die:

> 'I honestly do think, when you mention the word 'hospice', erm, I think, it's probably seen as a relief to some people that they are going there, and they know they are going to be looked after… I don't think anybody, once they've got over the initial scary bit of being told its terminal, I think they would rather be in there than anywhere else' (Daisy, hospice user)

Daisy did not express any fear about accepting hospice care and commented on the relief that older people may feel when they go to the hospice. Even though it is connected to dying, Daisy clearly stated that the prospect of being looked after at the end was a positive aspect and attraction of hospice care. The acceptance of death was also expressed by Clive, 73, who was open to the idea of either dying at the hospice, or at home while receiving hospice care:

> 'Well I know I'm going to die, I mean, it's not something I worry about, but I thought well, I said you know, I know so many people and they are wonderful people [at the hospice]. Whether I, I get admitted to the hospice at the end, or they come and, I mean the hospice also comes out to people who die at home, and err, so we'll see as we get a bit closer to the time' (Clive, hospice user)

George, 73, expressed his belief that this acceptance of hospice care, and of death is connected to age, and that as he has got older, he was less fearful:

> 'Things that used to frighten people years ago, maybe don't frighten them anymore. It's just I think they realise they think of things, and they process it, and it's not as frightening as what it was many years ago. Like Willen isn't as frightening to me now as it was many years ago' (George, not accessing hospice)

This point needs careful consideration because of the perceived barriers to accessing hospice care for younger patients, such as the fear of being labelled as dying and a hospice patient, or the stigma of hospice care and its association with death. The stigmatisation of hospice care provision will now be investigated further as the final section to this theme of finality.

9.3.3 Stigmatisation of Hospice Care

Stigma was discussed as either coming from the participants themselves self-stigmatising, or the participants demonstrating 'othering' where they attempted to distance themselves from the hospice and dying label. Participants also discussed the stigma they had experienced from their local communities. Barbara reflected on her reluctance to label herself in relation to the care she was receiving.

> Barbara: *I wouldn't have said I'm having palliative care, but I am*
>
> Interviewer: *Or end-of-life care?*
>
> Barbara: *Or end-of-life (laughs) no, no. Hospice... hospice, that word, it's like cancer you know?*

Barbara was conscious of a stigma around the terminology of hospice care, as well as the terms end-of-life care, and palliative care. She believed they were all synonymous with the care she accessed, care which she was reluctant to admit to receiving. She acknowledged that she knew she was terminally ill but being open about that in the interview was difficult for her because of the attached stigma. Frances was conscious of the ignorance in societies about death and dying, both from her own friendships and more broadly. This created a reluctance in her to admit to her prognosis, or discuss it with people because of their labelling of what a dying person should look or behave like:

> *'So I've had people go "Oh God you look really, really well" and then like a jokey, but you know it's not jokey "Are you sure you are actually ill?" and I go "ha ha ha" and I kinda wanna go "pffff you know what?"' (Frances, not accessing hospice)*

Frances also expressed an acceptance of the terminology, but wanted it to be unseen, because of the stigma associated with hospice that she experienced from her family:

> *'I think you can accept it, but you don't want it rubbed in your face, you don't want a big reminder of it… like mentioning hospice, I remember to my brother and my mum and dad, and you can see them going like, thinking, hmm, why are you going there? That's' where people go to die. So it is, as much as people see it as a wonderful place, and would do anything to keep it going, it's that stigma attached to it'* (Frances, not accessing hospice)

Emma had similar experiences with her peers who had a perception of a person with a terminal illness that was different to how Emma thought she presented herself. She expressed frustration similar to Frances in her interview:

> *'That's the other thing people say to me "You look really well!" Yeah for a dead man walking! (laughs) I mean what do they think I'm gonna look like, a fucking skeleton all of a sudden? (laughs)… Like when you say "I'm tired" and people say "I know how you feel". No, you ain't got a fucking clue! It's like you hit a wall, and you've got a ten-tonne block on top of you, everything hurts and you're like "and you're the same? Really?" (laughs)'* (Emma, not accessing hospice)

I found this particularly challenging to find two of my participants experiencing similar frustrations and realised that if these two women were known to the hospice, they may have been able to meet to share their frustrations. This could have possibly given some support or comfort, despite them having very different diagnoses, different care needs and different trajectories. It highlighted to me that this stigmatisation can cause psychological and social needs in patients, which could be potentially supported by hospice intervention irrespective of age or diagnosis. It was interesting to note this heightened awareness of societal responses to illness, dying and hospice care was more noticeable for the two youngest participants who were 47 and 49 years of age, as they discussed it extensively during the interviews. The stigma they experienced from professionals, people in the community and even family and friends highlighted an unexpected finding of this research which will be expanded on in the discussion

in Chapter Ten. The notions however of acceptance and inclusion, when focusing on hospice care is this final theme which is analysed next in the final section of this chapter.

9.4 Theme of Access and Inclusion

This was the least discussed aspect of hospice care – how people access, and who is eligible for hospice care. As mentioned in the introduction to this chapter, of the eight patients interviewed, three patients were currently receiving hospice care, and one was awaiting an initial appointment, so half had personal experience of how they were referred into the hospice service.

> *'It was on the recommendation of the, err, specialist at the hospital. They contacted them* [the hospice] *and recommended me and I went along'* (Clive, hospice user)

For Clive it was straightforward as he was accepting of the referral and complied with the recommendation from his specialist. Barbara explained her referral from her GP, who initially referred her for physiotherapy based at the hospice, but then to the day centre for more longer term and holistic social and emotional support, as an outpatient in their day provision called the Wellbeing Centre:

> *'Dr N got in touch with me and said, "How are you feeling and everything" and I said, "You know, I've been depressed and my tablets, I'm on sertraline and they've been doubled to 100mg, and she said, "I think I'm going to try and get you in on this wellbeing" so I said, "Oh really" and she said, "Yeah I think it really work for you, really do you good" and I had seen this going on, but didn't know how you got onto it, or what it was about, so I had a meeting, I came, they rang me, Dr N rang me, she had a chat with me and said "Oh I think yes definitely come on down, we'll have a chat and get you in"'* (Barbara, hospice user)

Other participants discussed how they refused the recommendation to refer for hospice care because they didn't feel it was appropriate or the right point in their life to be involved with the hospice. Helen recalled her visit from a nurse recently to her home:

> Helen: *She was asking, she was saying about the hospice, Willen Hospice, all the forms to fill in and things*
>
> Interviewer: *Were you persuaded? No?*
>
> Helen: *No, no, I don't want to go. I want to stay at home for as long as possible*

Even though Helen was an older patient, her desire to be at home influenced her decision to refuse hospice care. She was unaware that this could be provided in her own home, and some of her care needs may have been provided for by the hospice at home service. From Helen's recollection she focused on the administration of the referral process rather than any information she may have been given about the different options for hospice support. Emma explained she happened to meet a hospice nurse at an event locally for a charity which supported patients with the same life-limiting condition that Emma was diagnosed with:

> *'I met her, and she said, "I can be involved in your care now" and I went "Oh no you can't!"'* (Emma, not accessing hospice care)

Emma was very clear and defiant about her refusal of hospice care. Her decision was based on her assumptions that hospice care was for right at the end of life, and so, to her, was not relevant or necessary at that point in time, even though she was in her last year of expected life. She had though, considered her future as during the interview she discussed her strong association with researchers studying her condition, and how she agreed to donate her brain for research after her death:

> *'I'm under a research project, they are taking my brain when I die, I've told them they can, only when I'm dead, they're not having it while I'm still alive, you know'* (Emma, not accessing hospice care)

Although Emma had that assumption of hospice care being for right at end of life, she contradicted herself later in the interview when she considered the different aspects of hospice care, but maybe was relating them to her own needs:

> *'If you are going into a hospice, you're not going into a hospice to die all the time, sometimes you are going in the hospice for respite, sometimes you are going in just to, you know, because they've got therapies and stuff, they offer, they do offer erm, holistic, I was gonna say hallucinogenic but that don't (laughs) do that!'* (Emma, not accessing hospice care)

Two participants, Alan and Frances, had never been offered a referral to the hospice. Alan did not appear to be aware of his prognosis during his interview, and I was not sure whether this was because he had not been told, or he had been told in a way that he hadn't understood. This may be one reason why Alan did not feel he was at the right point in his life to be accessing any form of palliation including hospice care:

> *'I was pretty frail that day, and pretty rough that day when I saw them, and erm, they said, "Well err, it might be worthwhile considering palliative care." So, I said, "Surely, at the moment, that can be put on the side-lines." I don't know, I haven't been given any time or span of life to say it is gonna be one year, two years, three years, I haven't been given any idea of the problems I've got, what would cause what problems, sort of shall we say, for end of life'* (Alan, not accessing hospice)

Frances however was told she was palliative but was not offered any specific palliative support or the option of hospice care. This may have been due to the awkward manner in which she was advised of her terminal condition.

> *Frances:*   I heard the first word, like the care would be palliative. And I said, "What do you mean palliative?" and she said "Oh, because there is no cure, we are not curing you now, we are just extending your life". And that was the first time I had ever heard it, so I burst into tears, and she was really apologetic, she thought I knew this, and I said, "No!"

> *Interviewer:*   But they never offered you hospice to step in to help?

> *Frances: No, I was never offered…*

This recollection by Frances is particularly harrowing. Firstly, there was miscommunication among the professionals and assumptions made that she had been notified of her prognosis. Secondly, once she had been made aware, there was no discussion with her of what her support needs may be moving forwards, and the options to help provide for those needs. Frances had contact with the physical hospice location as the local lymphoedema service is based there, so in her view she had been in some form of contact with the hospice but had not actually ever received any hospice care provision. Daisy attended the same lymphoedema clinic based at the hospice site, but was referred through for hospice care from the same clinic:

> *'I was diagnosed with cancer, you've got to inform these people* [lymphoedema nurse] *because they are treating you, so I told her and she passed me onto the wellbeing centre at Willen, and I got a letter from them saying would I like to attend, come in and see them, and it went on from there. So, I had nothing to do with the hospitals or the doctors, it was all to do with the lymphoedema nurse'* (Daisy, hospice user)

It does raise questions about how people are referred, what information they are given to help support their decision about whether or not to accept hospice intervention, and why some staff appear to offer referrals and others do not. The different experiences of Frances and Daisy are very telling in highlighting the variation in hospice care access. During the interviews, patients were asked about hospice patients in general, and who is eligible for hospice care. The responses demonstrated a focus on cancer, as noted in the other data sources, however some participants did recognise that other conditions could be supported:

> *'There's other illnesses they can come in here for isn't there? I don't know but yeah, normally it's like the big cancer word'* (Barbara, hospice user)

> *'There are definitely other people there apart from cancer patients, but it's well known for its cancer health, and I think that's what everybody switches on when they hear Willen, "Oh cancer" It's the first thing that they think about'* (Daisy, hospice user)

Participants who were accessing hospice care drew on their own direct experiences of attending the day clinic and the other patients they interacted with, but recognised it was known mainly for cancer. All the participants were asked directly if they knew what life-limiting conditions hospices cared for, and for those not involved with the hospice the cancer specialism was still a dominant perception:

> *'Well, I don't really know, but people with terminal cancer usually go there and, err, yeah…. Well, I used to think so, but then I, talking to people, I think it's not only, it's also people who are really ill, that need, that needs that sort of care'* (George, not accessing hospice)

> *'Oh yes it could be any condition, it needn't necessarily be cancer, it could be anything, erm, it could be a tumour, it could be lung problems'* (Alan, not accessing hospice)

From the interviews, different routes of access to hospice care were identified, but all involved a healthcare professional. There may be issues concerned with the professionals involved in that referral process and how they elect who to refer, and also with the information given to patients to fully understand their prognosis and the options available to them. While this was the least considered aspect of hospice care, I argue it should be the most important, and this concept is investigated further in the discussion in Chapter Ten, after a short summary to end this chapter.

9.5 Summary

To summarise this chapter, all the participants engaged with and were positive about the hospice and its presence locally. There were differences expressed between those who use the hospice, and those who were not accessing any care from the hospice, and also between the younger and older participants.

Participants highlighted the support needed for social inclusion, psychological wellbeing, and support for family and friends. Less importance was placed on the more practical and pragmatic areas of medical care. A great variance was identified between people's needs and

experiences of care within this one local area. The culture and ethos of the hospice locally was identified and confirmed its standing and reputation, based on participant's own local knowledge and personal experience. The positivity for the hospice was most keenly seen when expressing its homeliness and expertise in managing end-of-life care, sometimes in contrast to perceptions and experiences of the hospital.

The belief that a hospice signifies death was apparent in this research, and dominated participant's thinking. The patients interviewed used their knowledge and experience of other deaths within and outside the hospice to shape their responses, as well as their experiences with family, friends, and their local communities in relation to their own prognoses.

The final aspect covered in this chapter was that of access and inclusion, and while it was the least discussed sub-theme during the interviews, it is the most interesting when considering who, why and how people access hospice care. The findings indicated some patients were potentially not given enough information to make an informed choice about whether to accept hospice care, and so relied on their own perceptions and experiences to influence their decisions. The variance with which professionals referred was also highlighted, particularly when two patients accessing the same clinic received different experiences relating to the referral process.

The next chapter combines these findings with the two previous chapters and engages in a detailed discussion in order to answer the research question on people's perceptions of hospice care.

10. Discussion

This research has addressed the question of how a community perceives its hospice care provision, and what this may mean for access to and inclusion within that community. The study has resulted in the collection of various sources of data as detailed in the previous chapters. These data have highlighted the perspectives of hospice care among some of the wider population of a UK town including patients, those who care for them, and the general public who could be either future hospice patients themselves, or family members of future patients. This discussion chapter will consider these perceptions and what they may mean for hospice care providers. This chapter is divided into three sections: Provision of Hospice Care, Positive and Negative Aspects of Hospice Care Ethos and Culture, and Hospice Care Access and Inclusion. In each section, I draw together the findings from this thesis and discuss these in relation to previous research, paying special attention where appropriate to the theoretical concepts of stigma and labelling, and therapeutic landscapes of care.

Before discussing those themes, it is important to spend some time addressing the issue of knowledge. The main aim of this research was to ascertain the perceptions of a population on hospice care. The experience and prior knowledge of the research participants was crucial to this study as it impacted on how they engaged and responded. Indeed, those experiences shaped and informed the participant's own understandings of hospice care provision (Hawthorne and Kwan, 2013). In the following sections of this chapter I discuss the contributions of the participants. However, there was an overall lack of knowledge among all the groups of participants surrounding hospice care provision, and palliative care generally.

As discussed in Chapter Five, the questionnaires for my study were completed by organisational staff who were in direct contact with the general public and could potentially refer people for hospice care. Among these participants, there was considerable uncertainty as they either left responses blank or stated, 'don't know'. Additionally, some of the focus group participants who were from the local population also acknowledged they were unsure what hospice care provision was in practice. This lack of awareness among the wider population concurred with survey-based research undertaken previously by Cagle *et al.* (2017), Kozlov *et al.* (2018), and Shalev *et al.* (2018). Unfortunately, while all three studies included a significant number of participants, they tended to focus on closed questioning,

therefore not allowing a greater freedom for participants to consider their perspectives on hospice and palliative care. However, their results demonstrated a lack of knowledge among the general population about care at the end of life in the US, and this research suggests a similar finding within the UK.

The patients who were interviewed also showed varying knowledge about types of provision, even those who were currently accessing hospice care. All were heavily influenced by their own experiences, either directly as a patient, or through family or friends that had received hospice care. The patients who were currently accessing hospice care only appeared knowledgeable about the care they had received personally, rather than any wider knowledge about the whole range of care and support services that the local hospice provided. For example, Barbara had only accessed the day hospice service and was unaware and slightly fearful of the inpatient unit and acknowledged she did not know *'what goes on up there'* (the inpatient unit was situated on the second floor above the day centre). To her, there was a topophobia about the upstairs section of the hospice, which represented death and dying because it was the inpatient unit, but also because she admitted she had not accessed that part of the building and did not know what care was provided there. The lack of knowledge had impacted on her perceptions of hospice care. Cagle *et al.* (2017) noted that the greater awareness their participants had of hospice care, the more they expressed a preference for that care.

This research goes further to suggest that a greater awareness of what hospice care is, could help to reduce the fear and stigma that comes from the unknown, as illustrated by the response of some of the participants here. There is a need therefore, for hospices to ensure their patients such as Barbara have that knowledge about the hospice and the care it provides, both within the hospice setting and out in the local community. There is a continued 'unknown' aspect to hospice care, with myths and misperceptions that need to be addressed (Cagle *et al.*, 2016).

Patients' knowledge of hospice care provision may be connected to the communication between them and the health professionals supporting them. In this research, one patient was referred by his doctor to the study as the doctor believed the patient was within the last year of expected life. However, the patient did not appear to be aware of this during the interview. Another patient participant disclosed that she found out she was having palliative

care by accident, as the health professional treating her thought she had already been informed. This highlights that patients may not be fully aware of their own condition, which would therefore impact on their awareness of options for their care. It also highlights a communication concern with the relationship between the professional and the patient. As discussed earlier, there is already a power imbalance in such a relationship and this can impact on patient autonomy and choice (Wilson *et al.*, 2013). What this research is suggesting is that there is also a gap in the knowledge of the patient. This could be connected to how much knowledge health professionals involved in their care have, and how able they are able to share that effectively with the patient.

This lack of knowledge around hospice care and the imbalance between the patient and the professional connects to the national legislation and guidance discussed earlier in Chapter Two. In the UK, the Ambitions Framework advocates several improvements that could be implemented in care at end of life (National Palliative and End of Life Care Partnership, 2021). In Ambition One it states that there needs to be honest conversations and clear expectations set out between professionals, patients and carers. Meanwhile, Ambition Six recommends professionals working with patients at end of life should have the ability to make knowledge-based judgements and be aware of legislation on personalisation of care (National Palliative and End of Life Care Partnership; 2021). Legislation such as the End of life Care Strategy (Department of Health, 2008) and Mental Capacity Act (Great Britain Government, 2015) have impacted not only on redressing the power imbalance mentioned earlier but trying to ensure patients have more knowledge and are able to make informed decisions for themselves about their care. Indeed, it has been argued that there has been a tangible cultural change in healthcare that allows patients to have much more autonomy and choice in their healthcare, that allows patient-centred care, and advance care plans to be integrated into modern practice (El Shirbiny, 2020). The governmental guidance therefore has acknowledged that the communication between patients and professionals is one area that can help improve care at end of life.

Of course, patients may not always want to know their diagnosis, prognosis or care options. This was identified in seminal work by Glaser and Strauss (1966), as discussed earlier in Chapter Three; they identified the various awareness levels of knowledge between patient and practitioner. Their findings of these knowledge levels among both patients and

professionals are still relevant today, as health workers are still the gatekeepers of knowledge on patients' health and care options. For example, participant Alan appeared unaware of knowledge about his prognosis, but his referral to this study, which was based on the eligibility criteria distributed to the clinicians requesting support for identification and recruitment of participants, suggests health professionals were cognisant he was in the last year of expected life.

Glaser and Straus' theory could therefore be useful for practitioners to guide through the communication processes as they support a patient's transition from curative to non-curative care (Andrews, 2015). When patients are given information, there can also be, as Glaser and Straus describe it, a form of pretence, where patients may choose not to agree with that knowledge, as was seen with some of the patients in this research, or they may pretend not to know, the latter being much harder to ascertain. Certainly, there was an element of patients not necessarily wanting to accept (Flaherty, 2018) or admit their prognosis was accurate (Cagle and Bunting, 2017).

Whether patients choose not to accept information, or there is some form of miscommunication by professionals, was a question considered by Richards *et al.* (2013) in their research with palliative care patients and carers. Therefore knowledge sharing between patient and professional may well be an issue that needs addressing. Professionals need to consider what information they hold about patients, and not only how to share it, but also to be aware of the patient's ability to understand and accept that information. The reasons for the unwillingness to accept their condition or prognosis could be due to the stigma around dying and care at end of life. This is addressed in this chapter in more detail in Section 10.3.

In earlier research from 2006, Chapple *et al.* concluded that patients needed to be more aware of the options and support available to them from palliative care staff; a point that has been reiterated recently by Russell *et al.* (2020), indicating this is an ongoing problem within healthcare for terminally ill patients. For patients at the end of life, an unwillingness to accept information on their health, or lack of awareness of their health prognosis, may also affect their willingness to consider any information relating to hospice care provision, depending on their perceptions of what that means. This will therefore, impact on the inclusivity and effectiveness of hospice care provision, because of their perceptions of what this means, and their understanding of being a hospice patient.

My research found that there was a need for information to shared more widely about hospice care. This concurred with Nagington *et al.* (2016) who identified there were very limited ways of obtaining knowledge, and it was primarily only through healthcare staff. Nagington *et al. (2016)* explored this in the context of district nursing, stating that the only method of patients acquiring knowledge about the support district nurses could offer, was from the district nurses directly. The findings here support that work as it was through hospice care staff that people were primarily acquiring knowledge about hospice care provision, whether that was as a patient, or through family or friends who had used their services. Within the focus groups, the participants who had some experience of hospice care took on a role of educating their respective groups about their knowledge and direct experience of hospice care. However, even this knowledge was limited and sometimes it did not reflect the actual provision of the local hospice. Many of the participants across all the data sources suggested they needed access to more information in order to better understand hospice services.

The sources of knowledge regarding hospice care then needs to be widened beyond hospice staff, to ensure more patients have the knowledge to make informed choices about their care. Relying on hospices to undertake this work may not be as effective as using other staff, including non-health professionals, due to the stigma around hospice care. People may not engage with a member of staff from a hospice, as was evidenced with Frances in this research. It may well be that information is already provided in some format, but it is possible that many people among the general public, or patients and even professionals are unaware of where it is, and how to access it, for example on websites or printed media. As Giddens (1991) noted, one of the keys ways that access and availability to care can be improved is by improving the relationships between the care structure itself and the communities it serves. Indeed, community models of care as discussed in Chapter Two, are becoming more prevalent in end-of-life care and are a key aspect of the concluding chapter of this thesis. The level of knowledge around hospice care among patients and practitioners, then, is a key finding of this research, and is an important area worth investigating further. The hospice, the local and national public health service in the UK, and communities themselves can either enhance or impede knowledge acquisition (Meusburger *et al.*, 2017). The limited knowledge of participants did, however, highlight some perspectives on hospice care, and these are

discussed in the chapter sections which follow, commencing with the provision of hospice care, before moving on to the themes of the positive and negative aspects of hospice care ethos and culture, and finally hospice care access and inclusion.

10.1 Perceived Provision of Hospice Care

One of the main themes that emerged for all the participants in this research was identifying the care needs of a hospice patient, and the care that was provided to meet those needs. All three groups of participants were aware of some of the types of provisions within hospice care. This section explores that awareness, considering their perspectives on the expertise of the care provider, and the various services that provider may deliver.

As expected, the participants who had direct lived experience of the needs of patients who are in the last year of expected life demonstrated the most understanding about the potential care and support needs of people who are dying. However, the needs they expressed were not always associated with hospice care. Some of the focus group participants had insight due to their own experiences of hospice care either directly, or through family and friends. This was also true of the questionnaire respondents, and of course some respondents were health professionals, some of whom were more likely to have direct end-of-life care experience to influence their understanding. In the first section of this theme, I explore the concept of the specialist nature and expertise of hospice care. The second part of this theme focuses on the types of provision identified by the participants.

10.1.1 Expertise of Care

One feature that was identified in the data was that of the specialist or expert nature of provision. Questionnaire respondents referred to provision being specialised and delivered by experts; a view also discussed by the focus groups and highlighted by some of the patients. However, there was still confusion and uncertainty, particularly as there was no consensus on hospice staff's expertise for specific terminal conditions. Some participants explained the expertise of hospice staff came primarily not from their medical provision, but from a

specialist understanding of the needs of patients at end of life, and an ability to provide comfort and 'homely' care environments. One focus group participant expressed that they perceived hospice care to be of a higher quality than that of other providers. This supports the review by Higginson *et al.* (2013) who concluded from that hospice care was considered to be of higher quality than hospital provision, particularly because of that ability to be less clinical and more homelike. This concept will now be explored in more detail.

Patient participants had varying perceptions of the expertise of hospice care. Some described the expertise in more general terms such as a specialist service at end of life for patients with complex needs or described their expertise in the non-medical aspects such as in supporting patients to feel special. The focus groups engaged in discussions around the type of care, primarily focusing on comfort and how hospice care was perceived to be specialist at providing comfort at end of life. Questionnaire participants clearly expressed a link between the physical location of the hospice as a place to receive the 'specialist' and 'expert 24 hour' care, and also mentioned that comfort was a key aspect of hospice care provision.

The idea of providing comfort and a comfortable environment have been evidenced in other studies exploring the meaning of end-of-life care (Pattison *et al.*; 2013), confirming this is a common perception of hospice care. Indeed, comfort is seen as a key component of end-of-life care (Coelho *et al.*, 2013) and it is an integral part of outcome measures for end of-life-care (Ho *et al.,* 2011). This is important, as if this is what people perceive hospices expertise is, then hospices can use that knowledge to help inform and educate people not only on the other aspects of their care but also the flexibility they have in providing that comfort, not only in the hospice setting itself, but also in people's homes, residential care facilities and secure units such as prisons, as this seems to be much less widely known.

This perception of the expertise of care can be linked to the initial purpose of the Modern Hospice Movement, as discussed in Chapter Two. Hospices were created to provide a service which was not being provided by the health service, that of specialist care for the dying, taking into account their holistic needs. The growth and development, as described by Seymour and Cassel in 2017, demonstrated a medicalisation of that care, and therefore a medical expertise of care at end of life. The historic understanding evidenced in this research of the specialist and expertise of hospice care staff is still present in societies today, with little change in understanding in contrast to the changes in hospice care access, delivery and provision. This

can be seen in the various job titles assigned to staff. There are 'clinical nurse specialists' and 'specialised palliative care services' which may or not include hospice care, depending on the local area and how services are organised. The mixing of terminology and labels for staff made it disorientating for myself as a researcher and so one may surmise it may also be confusing for patients and the general public.

Seeing care as specialist is an issue, however, particularly when considering the negative connotations around the medicalisation of palliative care. Mohamed *et al.* (2019) critiqued this medicalisation, as they found from their research with patients, that the medical interventions into dying had created an unrealistic expectation of life elongation, and a heightened anxiety around death. They concluded this was exacerbated by the use of medicalised terminology around the care of the dying, which had not transferred beyond healthcare staff. The expertise and specialist nature expressed by the participants in my research demonstrated a reliance, and possibly faith, that the hospice care provider was the best, and that only hospice practitioners could meet their needs.

These two important aspects of care were also considered in hospice care research by Graven *et al.* (2020). They posited that hospices should focus on demedicalising care in order to redress the balance between the medical and existential needs of patients. Certainly, in this research, both medical and non-medical needs were expressed, so while Graven *et al.* state they feel hospices need to demedicalise, the perception of the public may well be that they are already balanced between that medical and existential care. Further removal of the medical and professional dimensions of hospice care will require consideration of how patient perceptions may make this a challenging demand for hospice care providers.

When considering this expertise, one question raised is whether it is important for people to understand that care for people at the end of life is not the sole responsibility of hospices. The participants in this research expressed a perception that the hospice was the one-stop-shop for end-of-life care. There are specialist medical teams within hospital and clinics and also staff within residential settings who can also meet the palliative needs of terminally ill patients, however these were not considered by many of the participants. The hospital, when it was discussed, was seen as a lesser provider compared to the hospice. Hospice care may need to change its public image, not just as a medical specialist provider suggested by Graven

et al., but also to acknowledge and promote they are one of many providers who can support patients at end of life. The variety of that provision is discussed next.

10.1.2 Perceptions on the Variety of Hospice Care Provision

This study has endeavoured to look at hospice care holistically rather than segregating it into the disparate workstreams and services that hospices may deliver. Hospice care was perceived by participants as one homogenous care provider and as this study has shown there was little understanding of the different services within that provision. This section considers how the data evidenced a limited understanding of the different forms of care that could be delivered by the local hospice. Across all the data collected, various types of hospice care provision were mentioned; these were often heavily influenced by people's experiences. There are few studies which take a holistic stance when researching hospice care; most have often focused on specific strands of care provision for example: research on family support, hospice at home, befriending services, or inpatient services (Bucks *et al.*, 2017; De Vries *et al.*, 2012; Higginson *et al.*, 2010; Lan Fang *et al.*, 2016; Walshe *et al.,* 2016). This makes it difficult to view hospice care more broadly and explore how the different components are perceived and used by patients and understood by professionals and the general public.

The data suggested there was confusion about what types of provision constitute hospice care with a focus primarily on medical and practical services. This concurs with similar research undertaken by Bray and Goodyear-Smith (2013) with patients in New Zealand, and Nebel-Pederson and Sommers (2012) in the US, who concluded that patients were far more focused on the biomedical model of hospice care than the more holistic care provision that hospices provided. Where this research differs is that it evidenced that while there was a focus on the practical services such as family support, the participants perceived how that aided the psychological and emotional needs of patients, thereby indicating an indirect awareness of that holistic care.

Most questionnaire responses in my study tended to demonstrate a vagueness in clarifying hospice care provision. Some questionnaire respondents could identify individual provisions such as respite care, day services and counselling, however, this tended to be more from the hospice and hospital staff who would be expected to be more knowledgeable. In the focus

groups there was a clear emphasis on family and carer support and inpatient services. This was influenced by the experiences of some of the participants and their own family and friends. Focus group participants who had experienced hospice care directly, mentioned other forms of provision that could be classed as social and psychological care, such as the day care provision and respite care. However, these other areas of care were not widely known and there was a lot of confusion expressed as to what the hospice could provide, with conversation often referring back to the inpatient unit provision. Patient participants could only outline care which they had directly received either as patients themselves, or from experiences with family or friends, indicating a lack of general knowledge of other types of care. This included the patients accessing hospice care, who appeared not to have been informed of the range of services the hospice can offer, but only on the specific support they were receiving.

Thus, all the participants demonstrated gaps in their understanding of what hospice care could potentially provide. This confusion and gaps in knowledge could be through not understanding or recognising what care really means in the context of the term 'hospice care'. Milligan and Wiles (2010) defined care as the provision of practical or emotional support involving a network of actors and reciprocal dependence between all those involved including the carers and the cared for. They defined two types of care, in that it can be caring *for,* and caring *about*. In my research there was a mixed response to these two different types of care. The patients were more focused on the caring *about* aspects such as social contact, psychological wellbeing and family support, which can all be considered the emotional and relational features of care. For the focus group and questionnaire participants, there was more discussion on the caring *for*, that is, the act of care giving in a practical sense which included the inpatient unit, medical care and respite provision. This led to a dissonance in the concept of care between emotion and labour (Brown, 2003) as caring *about* has a more holistic and emotional characteristic and caring *for* is the more pragmatic and practical side of care. The differences in the perspectives of the participants in this research shows a deficit on both sides in terms of these two contrasting types of care. It means that while there is an assumption that people know what care is, this knowledge varies on an individual level, and this variance could impact on the acceptance and use of care services and meeting the needs of patients at end of life.

This therefore evidences the need to consider these two different aspects of care, that is, caring for, and caring about by the providers themselves, in order to identify and explain what form is being provided. It is also necessary to ensure the general public, which may include referrers, patients (current and future) and carers, are cognisant of not only the practical, but also the emotional and relational care that hospices can provide, to meet the needs of patients at the end of life. This could certainly help, indirectly, with reducing the medical focus of hospice care, but may not necessarily reduce the public's perception of hospice care being a specialist service delivered by experts. This perception links with the understanding of the ethos and culture of hospice care, which is the next theme discussed.

10.2 The Positive and Negative Aspects of Hospice Care Ethos and Culture

This section focuses on how hospice care was perceived through its ethos and culture. The culture of hospice care is linked to that of the communities and population it serves, because that is where its staff, volunteers and patients come from. The communication used within that population therefore is important and influential in creating and shaping people's perceptions and understanding. It is laden with meaning and when considering sensitive topics such as hospice care and the label of being a hospice patient, it can be very emotive. This research found there was an identified dichotomy of perceptions. There was a positive attitude towards hospice care and how well it was regarded, with a strong focus on the physical location of hospice care, and the fundraising and advertising that the hospice engaged in locally. In contrast to this positivity, there was also a negativity about the terminology of 'hospice care', the hospice association with dying, and as a place of death. This negativity also extended to the label of being a hospice patient, and a reluctance particularly from some of the patients themselves, to accept that label. These two aspects are discussed in turn in this section.

10.2.1 The 'Culture of Niceness' – The Positive Affection for Hospice Care

All the participants in this research demonstrated a strong affection for the local hospice, and found it challenging to consider any negative opinions, such as how it could change or improve. This strong affection is what Bray and Goodyear-Smith (2013: p212) referred to as a *'culture of niceness'* in perceptions of hospice care in New Zealand. Participants in my research did not cite many specific examples of good practice or justification for the high regard and positivity about hospice care locally. Instead, their responses were generic and vague, in line with Bray and Goodyear-Smith's earlier findings. The participants' positive attachments to hospice, their staff and care services, as evidenced in this research, appeared to be independent of whether they had any involvement or experience with the organisation. This concept means that people may not need to physically experience a hospice in order to have that understanding of its reputation as a therapeutic landscape (Lengen, 2015), and they may have achieved that meaning through interactions with others (Conradson, 2005). This would certainly include the communities, and local and national media. It could also be that the identity of the hospice building, and the care that it provides can create both positive and negative judgement within societies.

When prompted in the interviews and focus groups, the participants struggled to define hospice care but reiterated their views around the hospice and hospice care being *'wonderful'* and *'lovely'*. The high regard was also given in relation to the hospice staff, being described as *'fantastic'* and *'angels'*. This love was again prominent as many participants expressed an affinity with and positive regard for the hospice organisation and staff, and the actual hospice building. There was also a love of the hospice as a charity; indeed, the name itself evoked strong positive reactions in most participants, particularly around its charitable status and need for public funding. This love of a physical setting resonates with Tuan's theory of topophilia (Tuan, 1974), which he described as how people and cultures relate positively to their environment physically, spiritually, and emotionally. Here, we can apply this to the perceptions of the hospice expressed by the participants in this research. This topophilia demonstrates what Kearns and Gesler (1998) noted when they discussed that places achieve reputations, and an understood truth, which they described as a *'cultural construction that arises from experiences, perceptions, ideologies, attitudes and feelings'* (Gesler,1992: p17). This expressed love of the hospice, and love of the services they are perceived to provide may

mean that people do not understand or have an awareness of all the services that are provided, or indeed the services that are not provided. In the case of the latter as was highlighted in this research, respite care for families.

The focus on the physical location was seen in participants' responses on the aesthetics of the location. As mentioned in Chapter 2, the hospice is sited next to a lake, with view across the lake and parkland. Participants noted how 'peaceful' and 'calming' hospice care was because of its lakeside setting, demonstrating that affinity to the landscape and environment as Tuan (1974) first described. This concept of it being a positive place by a source of water is connected to emotional geography (Davidson and Milligan, 2004) which was later reframed as blue space geography (Foley and Kistemann, 2015). This was clearly a factor when the local area was being planned and designed, as there were significant natural and green spaces available; local rivers and canals were central to how the development of residential and recreational land was planned and included the creation of several man-made lakes for recreational use (MKDC, 1970a). Davidson and Milligan (2004) explained this connection to the aesthetics of physical space, when they stated that our emotions impact on how we interact and experience our physical environment. Even participants who had never visited the hospice were aware of its location beside a local lake, demonstrating how the perception of this environment influenced their understanding of the hospice, as discussed earlier. Davidson and Milligan (2004) advocated prioritising emotions when trying to understand how people perceive social spaces, linking back to the original concepts of therapeutic landscapes (Kearns and Gesler, 1998). Emotions were certainly expressed by participants in this research about the physical setting of the hospice and where, they perceived, hospice care took place. This was because of its homeliness, the expertise of staff and its location.

The high regard for the hospice as an organisation and its location may make raising awareness and understanding hospice care much easier. Their audiences will already have that positive outlook on care provision, and therefore may well be more amenable to new information on hospice care than anticipated. However, hospices also need to be aware of how having such an emotional connection to hospices and hospice care may impact on people's perceptions, interactions and expectations. This is particularly pertinent when one considers charities to be heavily reliant on donations and fundraising, relationships with businesses, local communities, volunteers and local primary health colleagues.

This topophilia could also mean it may be difficult for hospices to improve their services and widen their provision as they cannot ascertain from their local marketplace and stakeholders what improvements may be needed or desired locally. This is because, while hospices may conduct audits and evaluations of their services, if people have this overwhelming positive regard and love of hospice care providers, it can be difficult to openly criticise, albeit constructively, and so it will be a challenge to find out what is lacking or needs including, modifying or removing from their practice. his was evidenced in this research not only from some of the patients who were reluctant to say anything negative about the local hospice provision, but also from participants from the other data sources. Their love of the hospice provider was far stronger than any perceptions of the hospice requiring service development in terms of improvements in their provision of care.

For patients currently receiving hospice care, there was a discomfort to providing critique, this may have been possibly due to the relationship the patient may have had with staff. There may have been a perception that any criticism may impact on their current and future care, or a bias to give responses that are considered socially expected (Kamudoni *et al.,* (2018). It may also result from a just a lack of awareness of particular elements of service provision requiring improvements. For example in terms of diversification of patients such as ethnicity and medical condition presented. Indeed, the only commonality across the participants was their critique of the perceived lack of funding and provision of bed spaces, further indicating their focus on the physicality of hospice care within the building by the lake and its provision of inpatient care.

What this means then is that hospices need to be mindful of this love of the hospice, and how this may impact upon people's use of hospice care. While the government and charitable organisations are endeavouring to raise awareness of death and dying, and care at end of life, within UK societies, hospice care may be overlooked by such campaigns. This is also related to the drive for more home-based care, and also the assumption that people understand hospice care, due to the high regard and love for hospices both locally and nationally. However, this research demonstrates that while the topophilia for the hospice building and organisation may mean people perceive they know and understand hospice care, their level of knowledge is varied about what care is offered, who it is for, and how people access it, will vary. For example, people may not wish to 'bother' the hospice staff because they are seen

in such high regard, as expressed by Alan. Patients such as Alan in this research, may not feel 'deserving enough' to receive hospice care, or even attend the hospice building, seeing others as more needy. Hospices need to be prepared to address such perceptions in patients, and also their wider communities. It is important also for hospices to consider how this topophilia could affect their relationships with their communities when issues arise in care, for example, if the care received is poorer than expected, or an incident occurs, such as a safeguarding concern.

Participants were generally reluctant to think of any aspect of hospice care that could be changed or improved, perceiving it to be the best it could be, or even as one participant stated, better than other providers and the local hospital. It was curious then that the more general labels of hospice and hospice care evoked some negative responses linked to a labelling and stigmatisation of the terminology of 'hospice' and also the label of becoming a hospice patient, which are discussed in the next section.

10.2.2 A Hospice by Any Other Name – The Negative Stigma of Hospice Care

This section focuses on the label of hospice care in the context of care being provided by a locally based charitable healthcare organisation. One finding from this research was present across all the data sources; this was the perception that hospice care was synonymous with the 'hospice', that is, the physical building. The questionnaire responses, with the exception of those from some of the hospice and hospital staff, clearly expressed that hospice care meant care at the point of death within the hospice building. Within the focus groups this was also shown, although a member in Focus Group 1 used the discussion to inform the rest of her respective group about the community-based care her family had experienced, thus providing an alternative view for them to consider. Even the patients, including those currently receiving hospice care, indicated hospice care was given in the local building, primarily concerning the day provision and inpatient services. Milligan and Wiles (2010) suggested that care as a concept should not be limited to specific places and spaces; however, for the participants of this research, care was very clearly delineated within a specific site, that is, the hospice building. The concept of care was associated with tangible elements such as the staff or organisation delivering the care, and the physical location of that perceived

care. It may be that Identifying care as a concept may be too abstract or unworkable for the local population.

This association of place with specific care practices is found regularly within healthcare (Green and Lawson, 2011). It can be reinforced by hospice care providers themselves and positively encouraged in their architectural design (Worpole, 2009). Brown summarised it in 2003 when he posited that 'hospice' has three aspects – the philosophy of hospice care, the welfare policy, and the place. While the patients discussed the general culture of the hospice being homely and having an expertise of care, they primarily associated hospice care with the hospice building much more than its philosophy of holistic care, or any political context with the exception of acknowledging the need for charitable funding. Hospices themselves may believe that their ethos and philosophy are most important, but the community perceptions that I evidenced in this research still had that physicality of place as an important aspect of hospice care provision. If hospices want to raise awareness of their ethos and philosophy, they will need to be mindful of this strong, and potentially dominant focus among their audience on the physicality of place.

Across the globe, it seems that there is a stigma related to the terminology 'palliative' and 'hospice' as identified by McPhee in 1979, so this is not a new challenge for hospice care. Indeed, the stigma is still present as recent research investigating different aspects of end-of-life care reported stigmatisation and fear of hospice as part of their findings (Giesbrecht et al., 2018). Fear was certainly expressed by some of the participants in this research including those who were not accessing hospice care, indicating a possible reason why some of them would not consider hospice intervention. One manifestation of that fear is of the hospice building, which can be seen as a form of topophobia. Indeed, Crang (1998) identified this concept of a stigmatisation of a place, and concluded it was often due to the unequal relationships of people connected to that place. In this case, it would be the difference of the building being a place of care for people with a terminal illness, who would be considered unequal to those who are healthy. In order to address this topophobia, Hawley (2017) suggested that extending the term 'hospice' to 'hospice care' may help to reduce fear and stigma. In Taiwan there has been a shift to using 'supportive care' rather than palliative and hospice care because there are negative perceptions of these terms (Dai *et al.*, 2017). Similarly, in Scotland, there is a movement towards rebranding it as 'anticipatory care'

(Murray, 2017). Some hospice organisations in England have removed the word 'hospice' from their name, in an attempt to reduce the stigma, for example, Rennie Grove in Hertfordshire and LOROS in Leicester. The hospice care provider in the local area of this study may also consider changing their name in order to address local issues with stigma and fear of hospice care. However, as demonstrated in the previous section, the strong affection for the hospice and its very prominent reputation and branding locally could make this option unviable.

This study found there was a stigmatisation of the concept of hospice care, and the hospice itself as an organisation and physical place, particularly linked to the notion of hospice care provision being for the very end of life. The majority of participant responses established that they believed hospice care was inextricably linked with dying and death. This is a common view evidenced in other research (Cheng *et al.*, 2019; Van Klinken *et al.*, 2019). Seven of the eight patients interviewed and several of the focus group participants, had known someone who died in the hospice. This had influenced their beliefs around hospice care being a symbol of the finality of death. For the patients here, their experiences of family and friends' deaths had also influenced how they viewed the hospice. They all openly discussed whether they would consider it a possible option as somewhere for their own death. This was linked to their belief that the hospice is merely a place where people go to when they are about to die, evidencing a strong connection with place and end-of-life care only. This concurred with research into cancer patients' perceptions of palliative care by Collins *et al.* (2017). One of the themes Collins *et al.* concluded was that of diminished possibility, where palliative care was seen as *'a place to wait for death'* and *'an end to perceived hope'* (Collins *et al.*, 2017: p. 829). This view was also presented by Dixe *et al.* (2020) in their research on people's perceptions of hospice care in Portugal.

When considering that correlation with stigma, Goffman (1963) posited that once such associations are attached, they can be difficult to remove. Certainly, in the context of hospice care, this perception that it is for end-of-life care only has continued since their creation in the 1960s, indicating it will be a challenge for hospices to alter their perceptions among the public in that they deliver more than just care for the imminently dying within their physical locations.

Of course, as discussed in Chapter Two, modern hospices were originally created as places for people to die, where care and support could be delivered that was at that time unavailable elsewhere. Indeed, the physical design of hospices was originally to facilitate dying, in contrast to hospitals which were designed for curative treatment and rehabilitation (McGann, 2011). However, while there is now the trend within westernised culture and government policy to illustrate a preference for dying at home, this has not translated into a shift away from hospice to the home as a preferred place of death. As discussed in Chapter Three, this is an issue for the various policies and societal movements working towards community involvement in end-of-life care. In order for campaigns such as *Compassionate Communities*, and the Government *Ambitions Framework* to be effective, death needs to come out of the hospice and into the home. There is still a prevalence for death within a hospice within the local area of this study, as discussed in Chapter Two, where a significantly higher proportion of deaths above the national average are recorded as occurring with the local provider (Public Health England, 2017). The hospice has no reasoning for this anomaly of experiencing nearly twice the number of inpatient deaths compared to the national rate, but it could be due to its high regard locally, and that topophilia with the local lakeside environment.

It is interesting though that despite this popularity, there is still the negative emotional response to the hospice because of its connection to death and dying. This created a stigma connected to not only to the hospice building, but even specific parts of the building which are used for inpatient care, which was perceived by participants in this research to be a place of death, where one enters and never leaves. Patients using the outpatient clinic section of the building demonstrated a fear of this other section of the hospice, and distanced themselves from it, seeing those patients as different to themselves. The idea of the hospice building being primarily an inpatient setting, and the last resort for patients was seen in this research and concurs with other research on people's perceptions of hospices (Dixe *et al*, 2020).This identity which was established from the beginning of the Modern Hospice Movement is still prevalent even though the care provision has changed considerably since the 1960s. Thornham and Parry (2014) discussed the symbolism of buildings and concluded from their research into community buildings, that it can be difficult for physical environments to create a new identity, away from the original purpose of their design. A similarity with hospice buildings can clearly be drawn from this, particularly when this

research suggests that people still perceive the original purposes of hospices when considering hospice care, and the physical environment it is delivered in. This is in contrast to how hospices actually deliver their care, with a range of services delivered in many different settings. The use of the building is very different to its original conception, a divergence Thornham and Parry noted, and it is this divergence that is not always recognised by communities and society. Acknowledging and raising awareness of that divergence then will be useful for hospices to help eradicate these perceptions around their physical setting, and their care provision.

Half of the patients were reluctant to associate themselves with hospice care because of their fear that this association would cause them to become stigmatised with the negative identity of dying, and that they would be accepting they were nearing the end of their own life. These included patients receiving support from the local hospice, who either wanted to disassociate from the hospice, or certain elements of hospice care such as the inpatient unit. This concept has been noted in spatial stigma studies, where people from stigmatised geographical locations try to symbolically distance themselves from their location (Keene and Padilla, 2014). It is crucial that hospice care providers are not only aware of this stigma, but also consider how that may impact on referral, and how to redress this.

The time frame for hospice care was mentioned by most of the participants in this research as a way of identifying the uniqueness of hospice care provision. The focus groups and questionnaire participants expressed the perception of hospice care being for the final days or possibly weeks of life. This opinion was also reflected in data from the patients who were not receiving hospice care. They all believed that this was the expertise of hospices, in providing care only at this period in an individual's life. The focus group participants agreed that hospice care was for terminally ill people, and because they also confused hospice care with 'hospice', to them it signified a place to go to die rather than receiving any kind of curative treatment or long-term care. Hospice care was, therefore, in their view, primarily delivered in the time just before death. They did not consider in any detail the other forms of hospice care such as social contact, symptom control, or supporting psychological needs which could, and do, take place over several months or years of a patient's life.

Similarly, the participants who completed the questionnaire, generally gave comparable responses around this time scale of care right at the end of life. The only exceptions were

from two professionals who worked in the hospice and hospital respectively, who acknowledged hospice care could be over the course of several months, and so did not associate hospice care with that finality of death. This has to be a concern, as if the majority of a population perceive hospice care is only for the final few days or weeks of life, it is going to influence people's decisions to refer, or accept hospice care services. Therefore, the definition of hospice care needs to be made clear and explicit for local communities including professionals and patients.

If a timeframe is connected to that definition and is an eligibility criterion, this needs to be clarified. Equally, based on this, and other research investigating perceptions of end-of-life care, if a timescale is not a key aspect of defining hospice care, this needs to be more widely recognised than at present. If referrers or future patients believe that hospice care is solely for the last few days or weeks of life, referrals may not be undertaken early enough to have a positive impact on patients. This may well be the reasoning behind the government's push to improve the knowledge of practitioners discussing or providing any interventions, advice or support offered (National Palliative and End of Life Care Partnership, 2021). It could also be that a referral could be refused by patients if they feel it is too early in their trajectory, because they are not aware of the eligibility for hospice care, or the possible care options offered. This was evidenced in findings from patient participants Emma and George, who did not consider themselves 'at that point' for hospice care, even though both were in their final year of expected life. Johnson-Shen and Wellman (2019) researched the stigmatisation of care at end of life in their research with US citizens and their perceptions of palliative care. They believed this stigma was due to a clear delineation between curative and non-curative. It could be that people associate non-curative care with only that final stage of life, rather than potentially linking it to that received in the months or years before death. This is particularly pertinent when one considers that curative medicine is still more dominant within our biomedical culture, more so than preventative or palliative medicine (Fleuret, 2018). The findings of this study are in contrast to Johnson-Shen and Wellman, as treatment or care delivered by hospices was not considered so much in terms of curative and non-curative by the participants. This could possibly be a cultural difference between the UK and US due to how care is funded, or because Johnson-Shen and Wellman were researching the broader term palliative care, rather than specifically looking at hospice provision.

The late referral into hospice care can affect the type of care provided and the effectiveness of that care (Murray *et al.,* 2017). Allsop *et al.* (2018) identified that UK hospices still appear to be delivering what they define as a 'last weeks of life' service with 40% of referrals occurring within 30 days of death, particularly for older patients and those with non-cancer diagnoses. They suggested this would undoubtably impact on the quality of care that was provided. What is unclear from Allsop *et al.*'s research is whether the patients were offered hospice care earlier, and refused, or whether the referrers did not offer the option of hospice care until the patients were nearer to the end of expected life. Clearly, there is an issue then around perceptions of hospice care impacting on when people receive care, which can relate to when they are referred into the service. The findings from this study identified this particularly among the patients not accessing hospice care, who all expressed they perceived it to be for much later in their trajectories, despite all being in the last year of expected life. Even the patients who were accessing the hospice services still expressed the view of the care being for those nearer death and in greater need than they were. It would be interesting to ascertain if hospice providers are aware of this misperception among their patients, and the wider community.

Despite this strong attachment of the hospice building with hospice care, and the stigma of its connection with death, the older patient participants were generally more accepting of hospice care and the hospice itself, seeing it as a '*relief*' and a preferred place to be. They assigned a therapeutic value due to the comfort and homeliness they associated with the physical hospice, and therefore a neutral or positive attachment. The finality of death was still there, but as two participants expressed in this research, there was more acceptance of death and less fear of the hospice itself and hospice care. George and Helen's perceptions of age reducing the fear of death supports Ordille's 2016 paper on the phenomenology of end-of-life care. Ordille (2016) noted that as people age their perspectives on time, space, and the material world change, which impacts on their views of death. This then can be taken further as this research suggests, to state that older people are more accepting of hospice care. Conradson (2005) stated it is that relational, social interaction that impacts on the therapeutic value of a place. It may also be that older people are more accepting of hospice care because they are more aware of the holistic nature of hospice care especially the social contact and

psychological support that provides a therapeutic value. This can be due to experiences with family members or friends of similar ages, as evidenced by the older patients in this research.

That therapeutic interaction may be desired by older patients if they are experiencing issues that can be common in old age such as isolation, loneliness and depression (Burton-Shepherd, 2015; Grover, 2019). This could therefore influence a more positive and accepting regard for care and support from the hospice for an older terminally ill patient. Hanratty *et al.*'s 2013 research with older people in their last year of expected life found that older people felt disadvantaged dying alone and wanted the continued contact with professionals, a contact that could come with being referred into hospice care. Care at end of life for older people may well then be different to care for the general adult population. This is a point noted by Nicholson *et al* (2019) who considered the different needs of older patients, particularly those with frailty – a condition associated with age, stating that this can be challenging to fit within current palliative care models. This research would suggest the model of hospice care is actually a good fit to meet the holistic needs of some older people, indicating it may be the condition itself, rather than the age that impacts on the efficacy of care.

This research finding then should cause hospice care providers to consider whether their services are skewed towards the needs of older people, which may deter younger patients from accessing hospice care. This research has demonstrated that the issue of who and when a patient accesses care needs consideration by health professionals working within hospice care settings. How that care is accessed is discussed next.

10.3 Hospice Care Access and Inclusion

This section discusses the key areas of who is eligible for, and how people access, hospice care. Participants' responses evidence there was a variance again in knowledge and understanding. The section begins by looking at how participants perceived a typical hospice patient in relation to their medical conditions, needs, and other indicators to identify the perceived inclusiveness of hospice care. I end this section and the chapter by discussing the perceptions of this researched population on how people access hospice care.

10.3.1 Defining a Hospice Patient

All participants were invited to give their perspectives on who would access hospice care, thinking about their background as well as any medical condition or need. Responses varied depending on their personal and professional knowledge and experience. The questionnaire respondents demonstrated the least knowledge as many responses were blank, short, or vague, with some suggestions that it was for people at end of life and primarily for patients with terminal cancer. This association with cancer was also expressed by the patient cohort in this research, with uncertainty expressed about how the hospice may support patients with other conditions.

Other perspectives given by participants included a perception of hospice patients being very close to the end of life, an identifier that many of the patient participants not accessing hospice care could not relate to themselves or chose not to openly admit during the interviews. The focus groups also had the advantage of the vignette exercise (see Appendix 10) which suggested various conditions and backgrounds of fictional patients for discussion. This enabled these participants to have more dedicated discussions about specific types of life-limiting condition and personal attributes of fictional characters. The focus groups expressed the perception that hospices were 'experts' in cancer care and had a consensus that while hospice care may be for various medical needs, they perceived it was primarily for cancer patients. This was then justified by the groups when they suggested that other life-limiting conditions were either too specialist for hospice care e.g., dementia or motor neurone disease, or that for some conditions nothing, not even hospice care, could benefit the patient e.g., heart failure. The patient interviews and questionnaire responses also revealed a general view that the hospice was mainly, if not solely, for people with cancer diagnoses. They acknowledged other life-limiting conditions may be supported, but confirmed that as it is known for cancer, then that is the main condition supported by hospice care, and therefore was their area of expertise.

The predominance of cancer can be seen as a concern throughout development of hospice care in the UK. This then produces a circular phenomenon. If hospice care is known as primarily for cancer care, then patients with other non-malignant life-limiting conditions may be less likely to be referred or accept hospice care provision. This would then continue the dominance of cancer within hospice care provision and perpetuate the myth of a cancer

specialism. Researchers focusing on non-malignant conditions such as heart failure, dementia and chronic obstructive pulmonary disease have noted that there are lower numbers of such patients receiving hospice care, and palliative care in general (Cheang *et al.*, 2015; Hayle *et al.*, 2013; Kupeli *et al.*, 2016). If the hospice identity has such a strong association with cancer, it may be difficult for hospices to address this effectively within their local populations, and a national effort may be required, possibly removing the emphasis on condition-specific care, and instead focusing more on the complexity of need in the patient (Willis *et al.,* 2014). This is particularly pertinent with the local communities, who can then direct care to those in need in their neighbourhoods. For example in this study it was recognised that heart and respiratory conditions were significant causes of death in the local population (Public Health England, 2017), in contrast to the substantial numbers of referrals of cancer patients seen at the local hospice (see Chapter Two).

The focus group vignette activity highlighted prejudice, uncertainty and confusion among the participants in terms of who would be eligible for or even worthy of hospice care. This was not only in relation to their medical condition and need, but also their socio-economic background and personal circumstances. The responses from some of the focus group participants suggested that some patients were less deserving than others, for example, the fictional characters experiencing homelessness and incarceration, and the character described as being from a traveller background.

This can be seen as another form of stigmatism, where certain sections of the community, for example those from a traveller background, were deemed to have discrediting attributes which would make them less deserving or suitable for hospice care. This was noted earlier by Green and Lawson (2011) who considered in their discussion paper that this form of othering occurs in healthcare when certain patients are seen as outside of social networks and therefore less deserving. This point demands recognition because the vast majority of hospice care funding comes from public charitable sources. If the general public, the main funder, has a particular idea of the typical hospice patient and how 'deserves' hospice care, then education on the wider range of people that could, and indeed should, access hospice care is required to ensure the current inequity of service can be tackled. When discussing the ethnic diversity of hospice care patients, most people involved in the research did not appear to have any opinions regarding whether access is equitable or fair for the diverse local

population. They were not aware of the challenge of inequity and inequality within the Modern Hospice Movement in the UK that is currently reflected in patient demographics nationally (Calanzani *et al.,* 2013b), and also locally (see Chapter Two). Indeed, improving equity of care in all public health, including hospice care will necessitate breaking down those prejudices through incorporating communities, integrating local and national services, and potentially bringing palliative care more prominently into general health care (Hunter and Orlovic, 2018; HQIP, 2020).

Another perceived indicator impacting on eligibility for hospice care was the family background of patients. Some focus group participants believed that a support network of family and friends could provide a patient's care, influencing their perception that hospice was not required for that patient. They also perceived that the hospice would not accept them as patients, because of having their care needs already met. This is in contrast to some of the patient participants in this research, for example Alan and Helen. Both these patients perceived their family and friends' support at home meant they did not need any other support at the time of the interview. This may well have been true, but their lack of knowledge around what the hospice could potentially offer would indicate it may not have been an informed decision.

This patient perspective supports the findings by Romo *et al.* (2016) who noted in their research into family support that rather than it being something that would prevent the hospice accepting a patient referral, they concluded that having family support may influence the patient's decision not to accept hospice care when it was offered. Their research highlighted that having family support may, in the perspective of the patient, negate the need for hospice care. So, while the same outcome of not accessing hospice care would be achieved, the reason behind it may be perceived as different, that is, either the patient will not want it because of their family providing for their care needs, or the hospice would not accept them because of the family providing care.

This means that professionals referring patients to hospice care need to be aware of the family dynamics of people with terminal conditions, and how this can impact not only on their care needs, but also how they may perceive their own eligibility for hospice care. Local providers need to make sure their local communities and potential patients do not have a similar perception, creating a possible barrier to accepting care. This ties in with the UK

government *Ambitions Framework* (National Palliative and End of Life Care Partnership, 2021) which emphasises the need for practitioners to have greater knowledge of and confidence in supporting patients with life-limiting conditions. This may well be a strategy that could be undertaken locally to help address the high numbers of hospice deaths, by having well-informed referrers and carers who understand how much support can be provided at home, irrespective of families or carers present. This would also then help to solve the enduring problem of hospice care being associated with the physical building, with assumptions that all hospice care takes place within that building and establish effective relationships within the local communities.

Despite the negativity and prejudice expressed by the some of the focus group participants concerning the identifiers of hospice patients, for example patients without families, 'deserving' cases, or those with cancer diagnoses, they did, along with the patient participants and questionnaire respondents, reach a general, albeit vague, conclusion that hospice care should be for everyone who needs it, which contradicted some of their earlier discussions around specific terminal conditions. Participants could not, however reach a conclusion on how to identify who needs it, and what those needs may be. Equally no conclusion could be reached on how someone becomes a hospice patient, that is, the referral process, which is discussed next in the final section of this chapter.

10.3.2 Becoming a Hospice Patient – Inclusivity and Eligibility

In this section I consider the inclusivity of the hospice patient. I start by considering this from the perspective of the patients themselves, before looking at the practical aspect of how a person becomes a hospice patient, that is, the act of being referred to the hospice.

In this research, the main group of participants who were most focused on what is means to become a hospice patient, were the interviewees diagnosed with terminal conditions. These patients demonstrated, to varying degrees, a reluctance to openly recognise the label of dying, a label that was strongly associated with being a hospice patient. This reluctance was noted by Flaherty (2018) in a case study exploring the perspectives of a terminally ill patient. Flaherty proposed that there are two disparate labels for groups of people – the living and the dying – which can be difficult, particularly for hospice patients, because of the liminality

of their position (Flaherty, 2018). Hospice patients are indeed both living *and* dying, but as evidenced by the patients in this study, they may not want to associate with the label of dying. Alan stated that other patients had more specialised care needs than himself, and he was not at that stage of his prognosis. Similarly, Emma refused to accept the hospice care referral because she 'wasn't dead yet'. Barbara acknowledged that she perceived accepting the label of hospice patient may jinx her into dying earlier. This finding supports Hawley (2017) who noted that the fear and reluctance from a patient about accepting the referral and label as a hospice patient can be associated with the notion that avoiding talking about death will somehow prevent it from happening or avoid 'bad karma'. This is important as hospices and referrers need to be aware and develop strategies to be able to support patients, and their families who may have similar perspectives, as this could impact on a patient's ability to even be open enough to talk about possible hospice care intervention. Hospices need to reconsider how they present, if they do indeed present, a typical hospice patient to their local communities.

Certainly, in this research, Emma's comment of *'I'm not dead yet'* indicated a reluctance to be seen as quitting or giving up on life and seen as already dead. To be viewed as dying was different to the norm of society, which can create that felt stigma in patients (Grattet, 2001). They were experiencing the disconnect similar to Flaherty's (2018) findings mentioned earlier, and which Willig and Wirth (2018) discussed in their research into the liminality of patients between living as normal with friends and family, and the disconnection with society when perceived as dying. However, Willig and Wirth stated this disconnect was necessary in order for patients so they can transfer away from society to find their own meaning and sense of fulfilment in their lives, as this may be different to the societal 'norm'. This contradicted the views of the patients in this research who were still very much connected to their 'normal' lives, that is, the life they were living before becoming terminally ill.

This reluctance to transition between a living life and a dying life is important, because it could be integrated into hospice care services to help support a patient's psychological needs. Coming to terms with the realisation of death and how life may change prior to death are surely factors that may need addressing for patients referred to the service. If patients know such support is offered that may also then enable patients to feel hospice care is more

relevant to their needs as it is not just associated with the last stages before death or focusing on medical or practical needs.

This societal or relational stigma then concurs with Goffman's (1963) assertion that it was the interactions with others that impacted on the enacted, and the felt stigma of individuals. Goffman (1963) also considered people not accepting or hiding health conditions so as not to appear abnormal, but rather, fit in with society, reducing their perceived stigma due to their condition. While the patient participants were not hiding their own perceived reality that they were dying, there was a conscious effort by some of them to hide it from their friends and family because their abnormality was not the 'norm' expected by the friends or family of a hospice patient. They were dying, but they also did not feel their physical presentation was the accepted one for a dying person. This is an important factor in hospice care referrals and may impact on younger patients accepting hospice care. Hospices need to acknowledge these perceptions in patients, and also how the wider community perceives hospice patients, to help redress any felt or enacted stigma towards the adoption of the label of being a hospice patient. As discussed in Chapter Two, this is certainly some of the reasoning behind the many governmental and charitable foci on community involvement, engagement in awareness of care needs at end of life and supporting people who are dying within those communities. Society needs to change its perceptions of dying, and care for the dying in order to redress some of the stigmatisation.

Some of the patients interviewed used humour as a way to manage the perceived stigma they had experienced from societal responses to their condition and prognosis. Emma's responses during the interview were heavily laden with sarcasm, degradation and humour relating to her condition and her prognosis. The use of degradation and humour was a commonality seen by other researchers in patients to help manage their understanding and acceptance of their condition and prognosis (Emmerson, 2018; Gabbert, 2020). Emma also became an 'exemplar' of her condition, as Goffman (1963) described, as she was heavily involved with a charity that supported diagnosed patients and their families and commented that she had already donated her brain for research after her death. This acceptance of death, however, did not appear to be enabling her to accept a referral for hospice care, because it would mean accepting the label of being a hospice patient. This act, to her, meant she would already be dead, and dead to her family and friends. So, while it may be seen as a form of self-

stigmatisation in that being a hospice patient was synonymous with being very close to death or already dead, it was also perceived as a societal pressure for patients from the interactions, or anticipated interactions with others, as a form of social stigmatisation of dying patients (Link and Hatzenbuehler, 2016). For the patients, the distancing and othering from being identified as a hospice patient could have been due to their perception of an unequal relationship between living and dying (Crang, 1998). In this study a clear delineation was expressed between the outpatient users, that is, those who use the day centre service or support at home, and the inpatient service users, which was heavily associated with the final days of death. This again demonstrates that hospices, and potentially all palliative care services, need to be aware of the stigmas associated within the different provisions, such as the inpatient service. How patients access those provisions is the final consideration which is discussed in the next section of this chapter.

10.3.3 Becoming a Hospice Patient – Accessibility

The only way for people to access hospice care within the geographical region of this study was through a referral directly into the hospice system. This can be self-referral or a referral from anyone who knows the patient either professionally or personally. Therefore, referrals are a key source of palliative and hospice care research. Such data can help illuminate the process of becoming a hospice patient, and how it enables, or prevents patients accessing hospice care. The data collected for this study demonstrated the high prevalence of cancer referrals to the service, and a slightly skewed demographic towards female patients. Most notable was the lack of diversity in who was referring patients into the service, with only one referral outside of a health care setting, despite referrals being accepted from any professional, or family member, or the patient themselves. This statistic locally is concerning, and while reasons for this lack of range of referrals are not known, it may well be associated with the level of knowledge within the local communities as to who can be referred, and how patients are referred.

All the participants were questioned about how they perceived patients access hospice care. The focus groups did not appear to have any knowledge about referrals and access, including the participants with experience of the hospice. Members of Focus Group 3 discussed if there

was a panel based at the hospice, that would assess referrals and determine who would be accepted based on their circumstances. Another group believed acceptance was more likely due to whether the hospice had capacity, specifically within the inpatient unit to accept referrals. There was consensus, however, that it was a decision to be made by hospice clinical staff, rather than by the patients themselves. This demonstrates a biomedical and paternalistic view of hospice care provision, that it is a decision to be made by experts and professionals rather than individual patients and family members. This has to be a concern for hospice care providers as reliance on professionals could cause some patients to 'slip through the net' and never be offered hospice care, particularly from those professionals who are less knowledgeable about hospices, the support they offer, and holistic benefits they can provide. Equally noticeable from the questionnaire respondents was the prevalence of blank answers or admissions of 'don't know' from the questionnaire respondents when asked about access to the hospice. This level of knowledge was addressed in more detail in the first section of this chapter, but what it means here is that those questionnaire respondents, organisational staff who could refer patients into hospice care, may not do so because of their level of knowledge, competence or confidence. Rantanen's (2020) research with clinicians based in the UK discussed how the level of hospice care knowledge had impacted on referrals, for example they noted that there was an assumption that it was seen as a last resort. They noted that clinicians expressed negative connotations about hospices, and also a reluctance to refer because of the patient's negative perceptions of hospice care.

The patients I interviewed were not so concerned about how people access hospice care, but those who had been offered hospice care did recall their own experiences. Two patients were offered hospice care but refused to be referred. Patients refusing referrals is an aspect of hospice care that has received little research, primarily because it would be very hard to source participants and collate appropriate data on this. The interviews in this research however do enable a seldom-heard insight into a part of the eligible population who are not receiving hospice care. Helen did not accept the referral because she perceived hospice care to be an inpatient only service, and she wanted to stay at home. It seemed that she was unaware of the outpatient services, at home services, or family support that could be offered.

There is an issue around inclusivity if people assume all care is delivered in the one setting. This would then demand patients have to attend the setting. This can be physically difficult

for health reasons, but also the patient may not have the means to travel. The levels of deprivation and lack of car use in Milton Keynes would mean some patients having to rely on public transport, or somehow find the funds for private taxis. Patients may also have caring responsibilities of children, parents or even pets which may dissuade them attending. If they are not aware of the options for care at home, or other locations, they may not accept hospice care intervention. In order therefore to reduce the inequity of health care locally (Scott, 2015) perceptions like Helen's need to be addressed, certainly by the local provider, and potentially nationally.

The reason given by Emma was that she believed she was well supported by the clinical team who had been her primary contacts since her diagnosis. This concept of specialist teams for specific medical conditions being more able to provide palliative care, as opposed to hospices has been shown in other research (Brown *et al.*, 2014). Howell *et al.'s* (2010) research investigating complex blood cancers concluded that patients were reluctant to accept referrals because they had built up a good rapport and relationship with their clinical team and did not want to lose that continuity. This was certainly true for Emma, who admitted she would *'be lost'* without her key nurse and stated she would only consider hospice care when she was much further along her trajectory. This would indicate that some of the key policies and guidance discussed earlier in Chapter Two around end-of-life care, specifically those which called for more collaborative working between health care professionals, would be of benefit to enable end-of-life care needs to be appropriate assessed and offered to patients. That assessment and provision of care would not necessarily be from just from one provider, such as the clinical team supporting Emma, or Barbara's support from the local hospice, but a network of care including both primary, charitable, and community sources.

Thinking about how people access hospice care, it is not clear what information, if any, is provided to patients in this local area who may be offered or are considering hospice care. As seen with Helen, she did not appear to be aware of other support she could have been offered. In the US, recent research by Finnigan-Fox *et al.* (2017) concluded there was no formal information to help patients decide on whether to access hospice care. There appears to be no formal information provided within the UK for patients either; certainly the patients in this research were not provided with anything which detailed the services the local hospice could offer them.

Referrals can be considered a highly subjective way for people to access hospice care, due to the reliance on clinical judgement (Hui *et al.*, 2018). Referrals are reliant on the referrer knowing the process, knowing the options and possibilities, and referring appropriately, as well as ensuring patients' communication, cultural and spiritual needs are met (Lan Fang *et al.,* 2016). As this research demonstrates, there are organisational staff who do not understand the referral process or who is eligible for referral. Also, there is the need for patients themselves to be aware and understand what the referral means for them (Collins *et al.*, 2017), or even a desire to want the information to be made explicit to them (Richards *et al.,* 2013). Bray and Goodyear-Smith in 2013 advocated the need for information on hospice care, especially early in the care pathway to help encourage people to consider hospice services and remove the perception that hospice is synonymous with death. This may well have had an impact for some of the participants in this research. However, others such as Romo *et al.* (2016) suggested that hospice care decisions often come about through an interaction of beliefs, attitudes and behaviours as well as what a patient knows or does not know relating to their prognosis, and this was certainly seen among the focus group participants in this study. This connects with the drive nationally to increase awareness of death and dying, and care at end of life, to help change those attitudes and beliefs which could be impacting on access to appropriate care (Seymour, 2018).

Therefore, it is not just the information that can influence a patient's decision to accept hospice are, but also their own perspectives and beliefs which they may already have. This influence of beliefs was seen in the data from patients, for example Helen who, even when in direct conversation with a hospice nurse, still believed she did not require their support because she had her family, and she did not want to go to the hospice building. Alan, who had not been offered hospice care, was confident in his belief that he was not 'ill enough' for hospice care yet, as he could manage himself at home, with support from a friend. Unless he was given more information to help influence and modify his perception of hospice care, he would, therefore, be likely to refuse any input if it were suggested to him. Even the patients who were receiving hospice care did not appear to have been given any information on the other services the hospice provided outside the support they received. Barbara was a day patient at the hospice but did not know what the inpatient services were or how they

benefitted patients. She, therefore, wrongly assumed it was only for patients who had been admitted dying at the hospice.

There is also clearly a need for more education for the referrers themselves. Knowing when to suggest referral is a difficult decision for any referrer, even those with expertise in palliative care. Not only does the referrer need to be sure the patient meets any criteria for referral with regard to their medical prognosis, but also that the patient is supported psychologically to be able to accept that hospice care is appropriate for them for their life-limiting condition. This is especially important when considering, in the context of this research and the local area, anyone can potentially be a referrer.

An unexpected finding from the research was noted when one patient interviewed was referred into hospice care following attendance at a lymphoedema clinic (which is based within the hospice building). However, another patient who was interviewed also had attended the same lymphoedema clinic but had not been approached about hospice care. This is despite both patients being recognised as having life-limiting conditions, indeed both had terminal cancer. This can be seen as an example of the variance in hospice care access and inclusion, where two patients with similar prognoses following similar trajectories and receiving similar medical treatment from the same clinical team were not offered the same options for end-of-life care. The reason for this cannot be verified; however, it could be speculated that the referral experience variance seen with the two patient participants could be due to the patients being from different generations (Daisy, 81, was offered hospice care, whereas Frances, 47, was not offered any extra support). Another cause could be a result of the clinicians making a judgement relating to the support available to the patient from family and friends. Or it may be that the two patients saw different clinicians and one was more knowledgeable or confident about discussing hospice care than the other, or that the stigma of hospice care operated differentially on their decisions and actions. Irrespective of reasoning, the apparent variances demand further attention by providers.

The confidence and experience of healthcare staff in discussing end-of-life care has been researched considerably and shown to be a factor in the quality and use of palliative care (Lewis *et al.,* 2016; Pollock and Wilson, 2015; Russell *et al.,* 2020; Sutherland, 2019). Therefore, the knowledge, expertise and experience of anyone working with people who may

have life-limiting conditions needs to be considered, and support offered where necessary to enable them to be more confident in providing a possible route into hospice care if required.

Due to the inequity of hospice care provision discussed in Chapter Three, the referrals process has been increasingly researched to shed light on how this may influence not just hospice care, but palliative care more generally. Research suggests that clinicians appear to prefer a mixed approach of an automated and clinical-led referral process (Hui *et al.,* 2018), although how that would work in practice has not been discussed in detail. The real benefit could be that an automatic referral system may help with increasing appropriate referrals from less experienced and knowledgeable referrers, particularly those from a non-clinical background. Certainly, this research would suggest so, as professionals, patients and the general public were very uncertain about how to refer, who to refer, and when to refer someone in need of hospice care.

10.4 Summary

This chapter has brought together the various sources of data which identified how hospice care provision was perceived. A lack of knowledge was seen across the participant groups, with misunderstandings and uncertainty prevalent, causing assumptions and biases. The focus on hospice care being only for people who are at the very end of life for example, was a recurring point which impacted on how they perceived people are referred and the care they are given. The importance of the physical setting of the hospice was a crucial factor in shaping people's understanding of hospices in that it was primarily seen as a place to die. There was also ambiguity in that while people generally believed that hospice care should be for anyone and everyone, there were biases towards people who were 'more deserving' and those with cancer diagnoses.

The high regard for hospice care expressed by participants was used to highlight a positivity and general acceptance that while they did not know exactly what hospice care was, it must be exceptionally good because of the local reputation and high regard about the hospice. This included the hospice as an organisation, its charitable status, the staff it employs, and the aesthetic appearance of the physical location. The love and affection for hospice care, and

the identified topophilia for the physical place of the hospice was contrasted with the recognised stigma and fear of hospice care, being a hospice patient, and the topophobia of the actual hospice building because of its strong associations with death and dying. This created a distancing and othering, particularly noticeable among the patients in this research. This stark dichotomy has not been considered before in the forms of affinity co-existing with the fear of such a service, but it accurately reflects how these participants perceived their local hospice and the care services it offers, and as such demands greater awareness and understanding.

This bringing together of the theoretical aspects of stigma and topophilia for place and its therapeutic value needs greater recognition when services are planned for people at end of life, and for services to consider when they are initiating strategies to help reduce the inequities in hospice care provision. While it may seem having a positive regard and affinity for a service provider is an asset, it can cause issues when evaluating services, or overcoming perceived barriers of not being deserving enough for support. Similarly, while the stigma around hospices and hospice care may be known by providers, they may not be aware of how that may impact on patients, professionals and the general public, or indeed how that may transfer into the fear and stigma of being a hospice patient. This research has found and explored these perceptions within this cohort of participants from one regional area and discussed how the two concepts of both love and fear of hospice care can potentially influence how people interact and use hospice care.

The identification of these aspects is crucial to improving hospice care provision to widen access and inclusion, to consider the growing and changing needs of a growing and changing population, and to move forward away from the historical beliefs and assumptions around hospice care. Possibilities for improvement and change, along with the limitations of this research, are discussed next in the concluding chapter.

11. Conclusion

This thesis has set out to answer the question of how a local population perceives its hospice care provision. In this chapter I sum up the key findings and what this means for hospice care. I follow this with a summary of the limitations of this research, and possibilities for further studies to build and develop on these findings. Collectively, these may help improve hospice care accessibility, inclusion, and provision not just within this local population, but for hospice care providers nationally, and potentially internationally.

Through a qualitative and exploratory study, I have looked at a diverse participant cohort to ascertain and analyse their views and perspectives on hospice care. One of the unique aspects of this research project is the use of a wider range of participants going beyond those who work specifically in that industry and patients who are at end of life, but also considering those who work outside of health services, and potential patients of the future within the local communities. These views and perspectives are most telling in that they help us to understand how hospice care is perceived by a population. They can inform providers and commissioners of hospice and palliative care to identify gaps or misunderstandings in knowledge which may be impacting on access and inclusion. This is important, as surely a population cannot make an informed choice as to whether to request or accept hospice care if they have different understandings of what that means.

Therefore, from the findings discussed in the previous chapter I conclude that there are five key points that need addressing by hospice providers, but also to be acknowledged and supported by the wider communities in which they practice, including other health services and organisations that contribute to financing care at end of life. This is particularly pertinent considering the increasing focus on community models to improve palliative care through public health initiatives such as compassionate communities, cities, and neighbours. I start with the finding concerning the level of knowledge of hospice care, then consider the stigma attached to the labels of hospice, hospice care, and becoming a hospice patient. The third key finding was that of the focus on the physical location where hospice care is delivered, followed by the confusion around the timeframe for access to care. I end this section with the final finding which focuses on clarifying the eligibility for hospice care provision.

11.1 Addressing the Level of Knowledge

Throughout this thesis the key area that appeared to affect people's perceptions of hospice care was their own knowledge. For those who had experienced hospice care themselves or for someone they knew, a different understanding was expressed compared to that expressed by participants who had no prior connection with the hospice. Indeed, those participants with no direct connection to the hospice gained their understanding from the local presence of the hospice, as well as local and national media representation. As mentioned in Section 2.3, the local media focus tends to be concentrated on the fundraising aspects of the hospice, and so notable people identify the need and actions of hospices to fundraise as their primary knowledge of hospice care. Few media sources attend to the actual work of the hospice locally. Public health approaches to end-of-life care within the UK need to ensure they include staff both within and outside the health sector. The level of knowledge may impact on the accessibility of hospice care for people who are at end of life and are known to those professionals, for example, a homeless shelter worker or learning disability carer. That education can take many forms, including community events or training opportunities; however, direct contact and learning through experience is thought to be more intimate and effective than other forms of knowledge acquisition, evoking more meaning in terms of that knowledge (Meusburger *et al.,* 2017). It is certainly something that hospices need to consider if they want to challenge and change public perceptions of hospice care. It means educating people may need to come through providing that experience, rather than just supplying information.

This research demonstrates that varied knowledge of hospice care was seen across the participants of this research, and this may well be demonstrative of the wider population. Even those accessing hospice care in this study only knew about their own care and were unsure about any other services and support the hospice may provide. This means addressing the level of knowledge needs to be much broader than just focusing on a specific demographic, or even just current patients, the foci often seen in hospice care research. There needs to be a wider knowledge exchange between hospices and their local communities and populations globally. This is particularly important for younger people, as it was notable they were the least knowledgeable about hospice care, and the local population for this study is

notably younger than average. Within the UK, some hospices have already engaged with local education providers to raise awareness within school age populations (Palmer, 2019) and the compassionate city charter challenges schools to have specific policies in place around death, dying and bereavement (Sallnow and Paul, 2018). This may be better addressed by individual hospices as each one is unique and offers different services. It also means that knowledge exchange could be tailored to suit the specific populations that the hospice serves, for example, by considering different languages and settings where local communities may access information on health services.

That said, it may take a national awareness raising campaign to kick start more regional programmes, if only to try and counter some of the misperceptions of hospice care that are seen across the country. This may then help to redress the stigma and topophobia identified in this research, which is the next conclusion discussed.

11.2 Addressing the Stigma of the Labels of Hospice, Hospice Care and Being a Hospice Patient

Another challenge for hospices to consider is how the stigma around hospice care and the fear of being a hospice patient can be reduced. The stigma of death and dying and of hospice care within societies has perpetuated for a considerable time, hence the assumptions and misunderstandings evidenced in this research. One way to address this is proposed by Corrigan (2014) who stated that it is more powerful for people to have contact with the stigmatised rather than focusing solely on educational strategies, linking in with the previous conclusion concerning learning from experience (Meusburger *et al.*, 2017).   This approach was also suggested by a research participant through the questionnaires who stated that the hospice should:

'Share stories – publish stories online/post/newspaper. Let them sing about their patients, they lived a life!' (CS2Q10)

This approach of connecting with patients directly was also recommended by Nagington *et al.* (2016) in their research on palliative care within district nursing, when they suggested that

knowledge should be acquired in a patient-led way. Certainly, wider approaches involving the inclusion and engagement of stigmatised populations in other areas have been suggested (Werner and Scior, 2016; Morgan *et al.,*2018). However, there will be challenges with trying to incorporate this into awareness raising within local populations not least because of the taboo of dying, the stigma perceived and/or experienced by people who are dying, and the perceived vulnerability of the dying (Leming and Dickinson, 2020).

The integration of communities and their dying populations has also been advocated by others as beneficial when considering how people perceive health spaces such as hospitals and hospices (Skinner *et al.,* 2018). This approach of opening up public access to hospice patients directly may indeed be an effective form of education which would enable the community to construct new knowledge about hospice care and the hospice space. The focus group participants not only enthused about greater awareness and education around hospice care, but also a desire to be actively involved and engaged with their hospice, particularly from the participants who were currently experiencing homelessness. Of course, in situations such as the worldwide pandemic with the corona virus, this option may not be possible physically. However, as has happened in other areas of life during the lockdowns of 2020 and 2021, using technology and virtual connections could still be viable options which may actually be more appropriate, to show the diverse forms of care which are delivered within the local communities.

The concern at present with this as discussed in the introduction to this thesis, is that hospice care globally is currently inequitable, with higher numbers of cancer patients and fewer referrals for patients from minority backgrounds. This means, should any interaction take place between patients and the wider community, either locally or nationally, this factor must be considered otherwise it may, albeit indirectly, validate people's perceptions of hospice care being for a specific person or condition. However, this does offer an opportunity to include patients who may challenge people's perceptions of a typical hospice patient, for example a younger person, or someone with a non-malignant life-limiting illness.

As within any society, the local population studied in this research isn't just a population that has a hospice, but it comprises of communities that have a relational structure between themselves and local organisations. This would be seen for other hospices in different regions

of the UK, and in other countries. That relational structure includes the availability and access to other health services, public or private, such as hospice care. It is dependent on the relationship between the structure, that is, the hospice itself and the communities it serves (Giddens, 1991). The local area researched here has a diverse population with various communities across the region including different ethnicities and socio-economic groups. This means the hospice needs to involve those communities more in raising awareness and understanding of hospice care, to then help shape and direct that care in the future, rather than it being a didactic approach coming solely from the hospice, the NHS or a national charity such as Hospice UK. Raising awareness and understanding through collaboration between patients and communities, would then enable those stigmas which are still felt and experienced, to be challenged and hopefully eradicated from the local population.

There needs to be a change in the perceptions and understanding of hospice care provision, to benefit the local population and reduce the stigma that exists around the care they provide, their patients, and also the hospice building itself. The physical building is my next conclusion that I address.

11.3 Addressing the Focus on the Physicality of Hospice Provision within a Specific Location

There was a great deal of confusion around hospice and hospice care, with the terms being used interchangeably, and hospice care being used to represent a physical location, that is, the hospice building. Certainly, the location was very important locally in this study, particularly due to its setting and location. This demonstrated a widely held belief among study participants that hospice care was solely provided at that location. The location was especially dominant in this study due to its aesthetics of being a lakeside location, well-known locally as being a peaceful, calming setting. As the majority of hospice care is actually delivered within the community setting, often in people's homes, this is a key perception that needs addressing. Indeed, hospices not only provide care within the community, but also

support residential and nursing homes, prison services, and other sectors in providing care for people who are dying.

This focus on the physical setting also impacts on the divisions between the different services that hospice care includes. The majority of the population were aware of the inpatient unit. This research has demonstrated that there is a misunderstanding that inpatient care is solely for people in the final days of life, rather than for symptom control, respite or other reasons throughout a patient's trajectory. To help negate and change the perception that a hospice is a place to die, more recognition needs to be given to the considerable numbers of patients who leave hospice care and return to their homes with ongoing care and support. This current perception of inpatient care is a concern and can impact on whether people would consider inpatient care if it was offered to them. There was a tangible fear of the inpatient unit, which manifested even in a reluctance to want to physically enter the hospice building, or for current patients, to enter the inpatient area of the hospice setting. There was a demonstrable 'othering' of patients who are within the inpatient unit, and for many people, it was this provision which epitomised, or rather monopolised people's view of hospice care. This topophobia of the physical location of hospice care, and in particular the inpatient unit which represents it, therefore, does need a radical change in terms of how it is presented and understood within communities.

The work of the day centre is largely unnoticed by the local population despite it being an important part of the ongoing care and support given to patients. Other services such as alternative therapies, social activity groups and counselling were also not mentioned or discussed in any detail. If there is a focus on the physical aspects of hospice care, and where the provision is delivered, it needs to include all aspects of care and all locations, including home-based care to broaden out people's knowledge and understanding of the hospice setting and the care that is provided, linking with the first conclusion relating to the level of knowledge of communities. Other hospices may need to consider what services they provide, and how well known they are among their local communities.

It will be difficult to reduce the strong association people's perceptions have with the physical hospice building as the place of care, but I argue this is necessary as most care is provided within the local communities. One strategy may be to remove the word hospice completely.

Several hospice care providers in the UK have done this, for example, in Wolverhampton where Compton Care deliver hospice provision, and on the Isle of Wight where the Mountbatten Hospice is now known as only as Mountbatten. It may be useful to ascertain how effective such a change has been in altering people's perceptions of hospice care, and whether it has impacted on greater accessibility and inclusion for the populations served by those providers (Topping and Hartley, 2017). If the label of 'hospice' is to remain in use, it may need rebranding. Some hospices have tried this, using phrases like Hospice Without Walls (St Luke's Hospice, 2017) and Hospice at Home (NNAH, 2018). I argue hospice care needs to be acknowledged as one of these distinctions for it to become more equitable and accessible away from the perception of the physical hospice setting, and not seen as solely inpatient care for the last few days of life. This timeframe of when hospice care is delivered is discussed next in my fourth concluding point.

11.4 Addressing the Misperception of the Timeframe of Hospice Care

This research found that most participants' perceptions were that hospice care was for people when they are very close to death, that is, within a few hours, days or weeks, linking hospices therefore with death, and geographically, a place of death. This also evidences the earlier discussion point in Chapter Three around late referrals for end-of-life care, where Murray (2017) posited that late referrals had an impact on the effectiveness of palliative care. Having spent time connected to a hospice care provider for this research, it is clear that a significant proportion of care is delivered earlier in a patient's trajectory. That earlier support can be, for example, to stabilise symptoms, or for psycho-social interventions for the patient and their family. While there may be a period of withdrawal by the hospice once this care has been given, the hospice can and does provide care and support at various points along a patient's trajectory. This can take many forms including inpatient services, day hospice, alternative therapies, and community care.

The timeframe for these various aspects of hospice work was not well known by the research participants, and even medical staff who participated in this research were not confident in recognising how long a hospice can be involved with a patient. Of course, appropriate care is

provided whenever required to patients already referred into the service, but it seems that the timeframe of availability of hospice care needs to be more widely promoted to the professionals who can refer into the service, and to the general public. This may then enable prospective patients to be more aware of when they can be supported throughout their trajectory and not to assume that hospice care is only available in the final stages of life. It will also open up recognition of the wider range of services provided by hospices, demonstrating it is more than just care at the deathbed.

Patients, professionals and the wider population will benefit from seeing the hospice care which is delivered beyond that deathbed perception. Widening awareness of the timeframe of hospice care could then also help to divert attention away from the stigma of it being solely connected with the point at which death occurs. The principle of supporting patients to live a life while having a terminal illness is often cited by hospice staff and in hospice literature as an aim of their service. Therefore, by demonstrating that hospices can be involved in patient care for months, possibly years before death, it will strengthen that principle and ideally positively change perceptions of hospice care.

The elongation of care for people with life-limiting illnesses can also be linked to the public health approaches seen in the UK such as Compassionate Communities, where local organisations and populations are empowered to support and provide care (Kellehear, 2005). This includes care at the beginning of a patient's trajectory, where they may require significant psychological and social support. Widening the pool of potential carers and care providers to include a diverse range from the local communities may then help to confirm that caring for people at end of life is not the sole responsibility of professionals such as hospice care providers. Bringing care back into the local communities is a model that has been seen to work in areas of the UK, and in other countries, such as the Kerala region of India (Abdul-Azeez and Anbuselvi, 2021). Widening care providers beyond the perceived professional expertise of hospices may also increase the referrals into end-of-life care. This is because a wider pool of providers may have less stigma attached to their services, and improve the perceived eligibility criteria for that care, which is my final conclusion from this research.

11.5 Addressing the Variance in Perceived Eligibility for Referral to Hospice Care

This research highlighted a confusion among participants concerning who was eligible to access hospice care. The trajectory of a patient's prognosis was mentioned as possible eligibility criterion, that is, how close they were to expected death, as well as consideration of diagnosis, and availability of care and support from others such as family and friends. It seems that it needs to be made clearer who hospice care is for, and when, for there to be improved access to hospice care. Hospices do not select patients based on where they are on their prognosis trajectory, what terminal condition they have, or their family situation, contrary to the perceptions expressed in this study. The main route through which most people engage with hospice care services tends to be referrals from GPs, nurses and other specialist healthcare providers which, for this study, was predominately the palliative care team at the hospital. Therefore, the first target could be to increase the awareness among those professionals referring patients. However, what this research has also highlighted is that as anyone, even patients themselves, can refer into the hospice. Awareness raising arguably needs to reach beyond those who currently refer patients. This includes all those who could potentially do this, that is, those supporting someone with a terminal illness either formally or informally. It could also include the wider, general population because of that open approach to referrals.

This would certainly be useful when considering a community model of palliative care and support. The public health approach is to empower and broaden out care to be delivered by local communities, families, friends, and informal carers. For those communities to know there are options for when care becomes complex, too challenging to manage and deliver, where there they can access specialist advice and support from a local hospice provider would potentially help that approach to be effective. This would not necessarily mean the hospice 'taking over' but working alongside and collaboratively with a wider care network, as advocated by local initiatives and partnerships with other organisations, volunteers, families and the patients themselves.

This model would also impact on the perception of some of the participants that a person's social support network affects eligibility for hospice care. It is difficult to ascertain how supported a patient may be within their own social network, and it would be wrong to assume that, just because someone has a family, they are receiving appropriate support from that family. Hospice care, of course, is not just for the patient directly, but often includes care and support for the family and carers of a person who is dying. That support may not be known by patients and their support networks, further reducing the likelihood of them considering hospice care. This could be a concern as it is known that many families need support when caring for someone who is dying (Sercu *et al.,* 2018).

Therefore, hospices need to look at how they present their care to the local communities. Are they informing them about the support offered to families and carers? Are they clarifying that eligibility criteria do not include your personal family situation? Hospices need to consider these wider factors not only when discussing care options with new patients, but also informing colleagues who refer into the service. They may also want to consider broadening this within their marketing and promotional material, to show that having a support network does not negate you from receiving hospice care, and indeed, the hospice care does support those carers in their roles. For example, when raising funds for the hospice, it could be targeted fundraising for the family support work, thereby not only will it be raising vital funds, but raising awareness of this work among the local communities and businesses who support them.

As demonstrated by the referral data discussed in Chapter Two, the hospice received referrals primarily for patients with diagnoses of cancer. Addressing the perception of cancer specialism in hospice care is a challenge as it is a very strong image that hospices have had since their creation and growth in the last 50 years. There needs to be greater collaboration between professionals working within non-cancer conditions and hospice care providers to ensure those patient needs are being met, of course with the understanding that those needs may not be directly met by the hospice care provider, but from other professionals or informal carers with hospice support. Indeed, part of the hospice's work is providing training and support for other care organisations to appropriately deliver palliative care.

If a patient feels all their care needs are being met by their respective specialist health teams, this needs to be acknowledged and promoted in order to reduce the assumptions that hospice care is the *only* provider for people who are at end of life. This may be a difficult challenge for hospices locally, as a significant amount of their promotional work is centred around their specialism and expertise in caring for the dying. However, in order to increase access to palliative and end-of-life care and include people who may not wish to consider hospice care specifically, closer collaborative working with other providers and local communities may enable a more effective, efficient and inclusive local provision for people with life-limiting conditions.

Another challenge with eligibility is that of the referral process, and the varied effectiveness of referring into hospice care at different points in a patient's trajectory based on their diagnosis, prognosis, and the knowledge and competency of the referrer. Clearly there has been disparity with referrals in my study which demonstrated there were patients eligible for hospice care who had not been offered any services or were offered but not given enough information about the care options available by the hospice to make the informed choice as to whether to accept that care. As I have evidenced there is an issue with the level of knowledge and awareness among services that could refer into hospice care. Standardising referral criteria could be one strategy to help reduce that disparity and this was recommended by Hui *et al.* (2020) when they examined how patients were referred to outpatient palliative care services, and by Wallace and Tiernan earlier in 2012. Addressing these issues then could necessitate a complete change in the referral process system itself, or at least better education around the system that is currently in use, including its purpose, when to refer, how to refer, and what patients can expect when they are referred.

I now conclude this thesis with a consideration of the limitations of this research and potential avenues for further research.

11.6 Limitations and Future Research

This research, in its attempt to answer the research question of how a local population perceive its hospice provision and role within the local setting, has uncovered many questions

that will need further investigation. There were also several limitations to this research which will be discussed next alongside those future considerations.

As with any qualitative study there will always be some level of limitation because of the subjectivity of the participants and the data collected. The focus on the subjectivity of people's perceptions and understandings is not only a strength of this study but can also be seen as a limitation. As demonstrated, this study was heavily dependent on people's own knowledge, and their ability and willingness to express that during data collection activities. However, the purpose of this research, and the reasoning for the study dictated that a qualitative approach was required. Further studies following a more quantitative or mixed methods methodology could certainly help to expand on some of the findings in this research., for example, the diversity of referrals into hospice care, or the prevalence of the different services offered by hospice care providers. This would additionally help to validate the results of this study.

One limitation of this research was that it could not include perspectives of all marginalised groups including the prison community, people with disabilities, and people from ethnic minorities. Despite the geographic area being very multicultural, with a significantly higher proportion of people from non-white backgrounds than other cities in the UK, it proved too difficult to include that perspective within this research project. The limitations were largely due to the restrictions in time and capacity that came from operating as a sole researcher. It may be that future research could focus specifically on those under-presented minority groups within hospice care. Certainly, more needs to be done to help uncover why those populations are under-represented among hospice patients, and to identify the barriers to including those communities within research. In this research, I found that minority groups are hard to access without having a gatekeeper or local contact that could support engagement and outreach work. This could have helped the project considerably; however, it was challenging to find and engage those gatekeepers.

This research did try to investigate the availability and accessibility to hospice care for people with non-cancer conditions. It found that while research in this area has increased, it also needs further exploration to investigate the needs of people with life-limiting conditions and how best those needs can be met. Research is often carried out from the perspective of patients and/or professionals, focusing on specific non-cancer conditions, rather than

bringing together this knowledge and considering the inequity from a broader viewpoint, ideally researched alongside the local hospice provision. As a result of purposive sampling and targeted recruitment (see Chapter Five) I was able to ensure inclusion of patients with non-cancer conditions, which helped to cover that aspect. That said, this study also identified that patients with cancer were also not always offered the option of hospice care and support. We cannot allow the assumptions and generalisations made about hospice care, that is, its cancer bias, to blinker us to the possibility that there is also an inequity of provision among cancer patients, and therefore the reasons for that inequity may include a wider remit of patients than previously assumed.

The results of this study are of great importance not just for the hospice and local communities included in this research, but they are also highly relevant for other hospices and populations. Certainly, as demonstrated in Chapter Three, there has already been a growing body of research which has found similar results around the level of knowledge and uncertainty about what hospice care is, and who it is for. It may be beneficial for hospices to undertake similar research projects as completed here, to better ascertain their own local populations' perceptions of their care provision and role locally, which could be widened to consider greater representation than this study achieved, for example, including people with disabilities. This would then enable a form of validation as a series of case studies could be compared to give an improved, more generalised view of the situation nationally. Whether that could be stretched further internationally could be challenging, due to the wide variance in how hospice care is funded and delivered in other nations but is a possibility worth consideration.

Clearly, more research is needed within communities about their understanding of hospice care, and how they acquire that understanding as this has been shown to be a potential barrier to an equitable service. There also needs to be more focus on marginalised communities such as those experiencing homelessness, incarceration or other forms of deprivation, but that does not necessarily mean looking at these groups in isolation, but to ensure the wider population is a part of any discussion or study.

One of the unique aspects of this research is that I included patients at end of life who were not accessing hospice care at the time of their participation. There has been very little research undertaken into how this cohort of patients perceive hospice care, and their

reasoning for not considering, or not accepting, hospice care and support. I feel strongly this should be researched further as it is important to understand the reasons why this occurs. Those reasons may be connected to the referral process, the referrer, the patient, the family, their prognosis, their needs, the support they are currently accessing, or something else. Clearly, we cannot state that everyone who is at end of life should get, or even needs, hospice care, but understanding why some patients are not accessing it is important data that we do not have currently, although this research tentatively gives a first insight into that. Clearly, providing care at the end of life is not just the responsibility of hospices, there are many services providing that care. So, it seems somewhat unfair when hospices are considered inequitable, if there are justifications why, for example, people with non-cancer conditions have their needs met by other providers within the local communities.

Similarly, this research included the perspectives of a number of the wider general population who were not necessarily actively engaged in hospice care. Research into the general public perceptions of end-of-life care has been limited, and most studies have been undertaken in the US. This is a gap that needs filling. As potential patients, or family and friends of potential patients in the future, surely it is important to include this population in any study about hospice care, or design research focusing on that general view of a population. This research has demonstrated how crucial it is to hear that perspective, and therefore continuing further research with the wider population, particularly younger people should be undertaken.

This research was limited because of it being a PhD: a funded and time-limited project undertaken by one researcher. Those limitations meant I could not successfully navigate around the difficulties with recruitment to ensure I included the perspectives from staff working with the prison sector or ensure some representation from local minority ethnic groups and people with disabilities. The numbers of participants could also have been increased to be more representative if more time and support had been available. As a qualitative study I was able to collect rich and diverse data, but it could have been more inclusive if I had been afforded more time or worked within a team on the project. For future research adopting a similar methodology, it would be worth considering a team approach, possibly including researchers from a hospice and non-hospice setting to help with recruitment issues, access, and provide a greater input on the data analysis itself.

11.7 Concluding Summary

This research has demonstrated a strong connecting theme of awareness raising and knowledge sharing as a means to improve perceptions of hospice care, access and inclusion. I envisage this education to be a localised collective from all communities including health care services, charities, social services and housing, education and community organisations, patients, families, friends and carers. The public health model epitomises such a collective where one can learn from the other, to break down the barriers and stigmas associated not just with death and dying, but with hospice care, palliative care and end-of-life care. Hospice care should not be seen as the gold standard, the experts, or the gold ticket for a good death, but rather as one of several providers supporting their communities to care for their dying. If this were achieved, we may see fairer, more equitable care at end of life, including hospice care, with broader more inclusive provision for all people with life-limiting conditions.

Finally, I contend it is important that there is a need for strong supportive qualitative research literature. This literature should identify, explain and disseminate the perspectives of patients, carers, professionals, and local communities, allowing them to be actively involved and participating in the design, delivery and development of services. Hospice care is an area of medicine that the UK is renowned for throughout the world, and considered one of the best, if not the best, providers. We need to ensure we continue to research, develop and tailor our hospice care provision to make sure it is fit for purpose for our ever-changing communities, through active involvement and engagement with those diverse populations. From this research it is clear that people within local communities want to be involved, and they have a lot to tell us.

Appendices

1-   Conceptual Map of Theories Used in Study

2-   Profiles of Participants

3-   Information Sheet for Patient Participants

4-   Consent Form for Patient Participants

5-   Information Sheet for Focus Group/Questionnaire Participants

6-   Consent Form for Focus Group/Questionnaire Participants

7-   Questionnaire

8-   Interview Guide

9-   Focus Group Guide

10-   Focus Group Vignette Activity

11-   Analysis of Questionnaire Data: Code and Theme Map

12-   Analysis of Focus Group Data: Code and Theme Map

13-   Analysis of Interview Data: Code and Theme Map

14-   NHS HRA Ethical Approval Confirmation Letter

15-   Open University Ethical Approval Confirmation Letter

Conceptual Map of Theories Used in Research
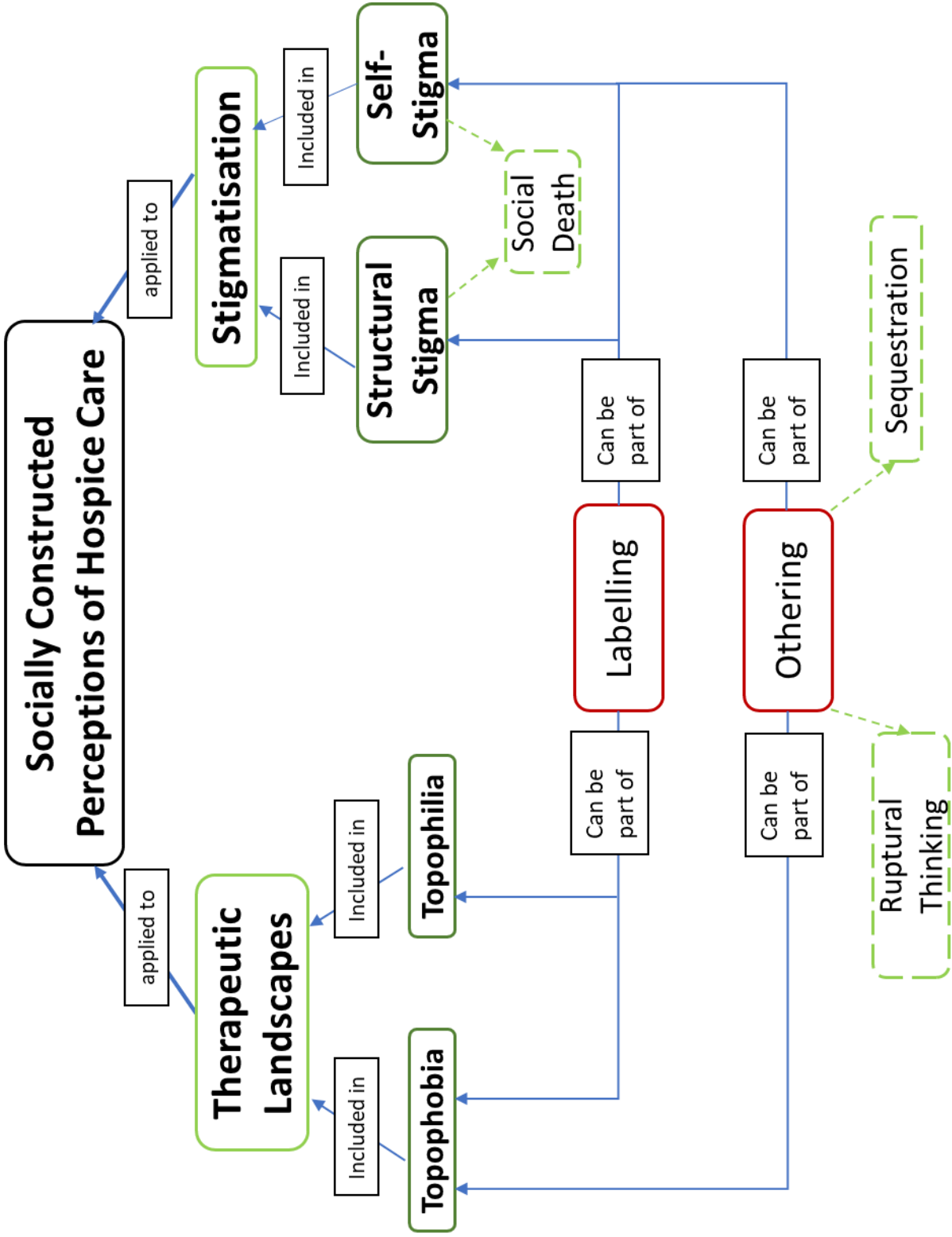
Appendix 2:

Participant Profiles: Patients

The profiles listed here are for the patients who participated in this study. As can be seen their ages range from 47yrs to 89yrs and presented with both malignant and non-malignant conditions. Their family and social circumstances influenced their responses considerably as they considered the care provided by friends and family, as well as the support needed by their family and carers. Therefore, these profiles explain the background and circumstances of each participant in more detail.

Alan was a 75yr old white British male who lived in his own home with a friend who supported him with his care needs. Alan had heart failure, alongside other conditions impacting on his ability to manage day to day living. Alan did not appear to be aware of his prognosis but did express a desire to want to stay at home for his final stage of life.

Barbara was a 57yr old white British woman who lived with her long-term partner in their own home. Barbara had a history of cancer which had been treated but had returned and was now terminal. Barbara worked part time running her own coffee shop locally. Barbara enjoyed using the day centre provision at the hospice but was reluctant to consider what she would want when her health deteriorates, and she is close to death.

Clive was a 73yr old white South African man who lived alone in a sheltered housing scheme property. Clive had a diagnosis of lung disease which was terminal and impacted on his mobility and day to day living. Clive enjoyed visiting the hospice for support through the day centre provision and was accepting of the possibility of going to the hospice as an inpatient for his own death.

Daisy was an 81yr old white British female living alone in her own home. Daisy had a diagnosis of cancer and was being supported by the hospice and her family for her care needs. Daisy enjoyed outpatient support from the hospice and expressed a desire to remain at home if possible as her health deteriorated.

Emma was a 49yr old white British female living in her own home with her husband and four teenage children. Emma had a diagnosis of Progressive Supranuclear Palsy, known as PSP, a degenerative neurological condition. Emma was heavily involved with the PSP

support charity and PSP research community. Emma's family were supportive and receiving support to manage and care for Emma from the neurological team at the hospital. Emma expressed a desire not to be connected to the hospice, until at the very end of life when she would want to be admitted to the inpatients. Emma did not want to die at home because she was concerned how this would impact on her family.

Frances was a 47yr old white British female living in her own home with her long-term partner and 23yr old son. Frances had breast cancer which was treated 10 years earlier. Frances in recent years developed cancer elsewhere in her body which had spread rapidly. Frances received some support from friends. Frances felt her family were struggling to accept her prognosis. Francis had not considered where she would want to die.

George was a 73yr old black Caribbean man living in a local housing trust property with his wife. George had a diagnosis of lung disease and was in the stages of being referred to the hospice for support. George had a supportive family locally and in the Caribbean. George had not considered where he would want to die but was accepting of hospice involvement.

Helen was an 89yr old white British female living in a local housing trust property on her own. Helen had a diagnosis of cancer which she had received 2 years ago, and it was now terminal. Helen was supported by her son who visited regularly and had a supportive group of friends. Helen strongly expressed she did not want the hospice involved in providing any support or care.

Participant Profiles: Focus Groups

The intention of the focus groups was to offer the opportunity for members of the public to express their views on hospice care. As such there was no plan to undertake any purposive sampling, or collate details of the level of understanding, knowledge or experience of hospice care prior to the focus group activity. The groups did comprise of people with varying degrees of experience of the local hospice, which informed their responses. Those responses were then discussed by the group who were not as knowledgeable. For example, those with direct experience of the local hospice used this to form their perspectives and educate the rest of the group on their perceptions of the care that was provided.

Focus Group 1:

Angie – Angie was a 45-54yr old white British woman who had experience of the local hospice due to her sister receiving hospice care both as an inpatient and outpatients' services in their own home.

Brenda - Brenda was a 65-74yr old white British woman who had experience of hospice care, which was given to her husband at home, and as an inpatient. The family had also received bereavement support. Brenda's mother died of cancer but had not received any hospice care intervention.

Celia – Celia was a 25-34yr old white European woman who had no prior experience with any hospice.

Dora – Dora was a 65-75yr old white British woman who had experience of a friend's child in a children's hospice in a different geographical region. Also, as a child her neighbour had been admitted and died as an inpatient in an adult hospice in a different geographical region.

Ed – Ed was a 35-44yr old white British man who had no prior experience of any hospice.

Focus Group 2:

Alison – Alison was a 45-54yr old white British woman who had cancer and was knowledgeable about some palliative care services in the local region but was not currently accessing any hospice support. Alison had known a friend who had been admitted and died at the local hospice

Bea – Bea was a 55-64yr old white British woman who had experienced hospice support for her dad which was delivered in his own home.

Cassie – Cassie was a 35-44yr old white Eastern European woman who had no prior experience of hospice care.

Debbie – Debbie was a 35-44yr old white British woman who had no prior experience of hospice care.

Eric – Eric was an 18-25yr old white British man who had experience of the local hospice supporting his grandmother as an inpatient.

Focus Group 3:

Aaron – Aaron was an 18-25yr old white British man who had no prior experience of hospice care.

Brian – Brian was a 35-44yr old white British man who had experience of a friend being admitted and died at the local hospice, and a friend's mother who had received hospice support locally.

Cliff – Cliff was a 55-64yr old black British man who had experience of two friends who had been supported by the local hospice inpatient services.

Dillon – Dillon was a 25-34yr old white British man who had experience of his brother having cancer and being supported at home but was not hospice care. Dillon's mother worked as a care worked in a nursing home and delivered palliative care to residents.

Emile – Emile was a 25-34yr old black British man who had no prior experience of hospice care.

Participant Profiles: Professionals

The questionnaire completed by professionals allowed a limited amount of data to be collated about their individual situation. Each respondent detailed their age and gender. Some offered their ethnicity, but not enough to make this a viable consideration in this research. Respondents also identified which profession/industry they worked within.

Respondents were not asked about their personal or professional connections with hospice care and palliative care, although some did offer this information in their answers.

Profession Identifier	Age Band	Gender	Ethnicity
HS1	56+	Male	White UK
HS2	41-55	Female	White UK
HS3	26-40	Female	White UK
HS4	56+	Male	White UK
HS5	26-40	Female	White UK

GS1	6-40	Female	White UK
GS2	41-55	Female	White UK
GS3	41-55	Female	Middle East
GS4	41-55	Male	Black African
GS5	26-40	Female	White British
LS1	26-40	Female	White UK
LS2	41-55	Female	White UK
LS3	26-40	Male	White NON-UK
LS4	56+	Female	Black African
SS1	26-40	Male	White UK
SS2	41-55	Female	Black African
SS3	56+	Female	White British
CS1	26-40	Female	White NON-UK
CS2	26-40	Female	White UK
CS3	41-55	Female	White UK
XS1	41-55	Female	White UK
XS2	56+	Female	White UK
XS3	26-40	Female	White UK
XS4	26-40	Female	White UK
XS5	56+	Female	White UK
WH1	56+	Female	White British
WH2	41-55	Female	Black African
WH3	26-40	Female	White UK
WH4	56+	Female	White British
WH5	41-55	Female	White UK

Hospice Care in Milton Keynes Research Project

Information for Prospective Participants

Zana Saunders, PhD student, The Open University, Walton Hall, Milton Keynes, MK76AA

E-mail: zana.saunders@open.ac.uk Tel: 01908 652306

Who am I?

My name is Zana Saunders and I am a PhD student conducting a 3-year research project with The Open University. This research has been approved by the NHS London-Stanmore Research Ethics Committee.

What is the research about?

I am researching hospice care within Milton Keynes. I want to find out what people think about hospice care and how that may affect how the care is used locally.

Why is this important?

Hospices provide a valuable service to local communities, and it is important that hospices understand their local communities. By doing this research, I hope to make sure that the views of the community are heard and understood within Milton Keynes, but which could also benefit other hospices and end of life care providers throughout the UK.

How will I undertake the research?

Case studies are really useful in research, especially in health and social care so I will be doing a case study of Willen Hospice. This means getting information from lots of different sources including patients, professionals and the local community. I will do this by using different methods including interviews, surveys and focus groups. Interviews and focus groups are expected to last no more than one hour, and breaks can be made at any time. These will be audio-recorded.

Why am I asking you to take part?

I want to hear your views and opinions on hospice care, and will then bring all the different voices together to see what themes emerge. Your voice is important.

Will the information I collect remain confidential?

Yes. I will not use your name in any write up of my research, and your views and contributions will be treated confidentially, unless it is felt there is a safeguarding issue related to what has been disclosed. All materials may only be discussed with my supervisors Dr Sam Murphy and Dr Kerry Jones (contact details below). All contributions will be anonymized and identifiable material will be destroyed no later than 6 months from participation, including the audio recording and contact details after transcription. All transcriptions and study notes will be securely stored at all times. Anonymised data will be stored and may be used for further research in an open access environment, and there will be no identifying material within it. All information will be handled in accordance with the Data Protection Act 1998.

Can you leave the research?

Yes. You are free to leave the research without reason at any time if you no longer wish to take part. If you choose to leave the research before I begin analysing the recording transcript, then all of the information you have given me will be destroyed, unless you consent to your information being used in this study. Once data analysis has begun, the data will then be anonymised and so it will not be possible to remove this from the study.

Will there be any risks associated with you taking part?

I do not anticipate there will be risks associated with this research, however the subject matter is quite sensitive and could be upsetting at times. If you feel you would like to talk to someone about this support can be arranged through Willen Hospice. Taking part or withdrawing at any time from the study will not affect any current or future support you or your family may require. I shall be happy to discuss anything with you at any time during the research. My contact details are on this information sheet.

How will the research be used in future?

Research results will be written up for my PhD thesis and may be published in academic journals and used for educational purposes. No individual will be identifiable, and anonymised data will be stored for possible future research projects in an open research environment.

More information:

Please contact me if you would like to discuss any aspect of this research or require any further information. My e-mail and phone number are at the top of this sheet.

If you want to talk to someone else about this research from The Open University, you can contact the Director of Postgraduate Studies: **Dr Lindsay O'Dell, Faculty of Health and Social Care, The Open University, Walton Hall, Milton Keynes, MK76AA**
Many thanks for considering this request.

Zana Saunders

Consent for Involvement in the
Hospice Care in Milton Keynes Research Project

Name of Project Researcher: Zana Saunders

I would be grateful if you could please read the following and then sign at the bottom – thank you

Please initial box

I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.

I understand that my participation is voluntary and that I can withdraw at any time up to the end of the data collection stage without giving any reason.

I understand my contributions will be audio recorded, transcribed and stored securely in line with the Data Protection Act 1998

I have been assured that my confidentiality will be protected as specified in the information sheet.

I agree that the anonymized information that I provide can be used for educational or research purposes, including publication, for any future study that has received ethical approval.

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Name of participant   **Date**   **Signature**

_____   _____   _____

Name of researcher   **Date**   **Signature**

Hospice Care in Milton Keynes Research Project

Information for Prospective Participants

Zana Saunders, PhD student, The Open University, Walton Hall, Milton Keynes, MK76AA

E-mail: zana.saunders@open.ac.uk Tel: 01908 652306

Who am I?

My name is Zana Saunders and I am a PhD student conducting a 3-year research project with The Open University. This research has been approved by the NHS London-Stanmore Research Ethics Committee.

What is my research about?

I am researching end of life and hospice care within Milton Keynes. I want to find out what people think about hospice care and how that may affect how the care is used locally.

Why is this important?

Hospices provide a valuable service to local communities, and it is important that hospices understand their local communities. By doing this research, I hope to make sure that the views of the community are heard and understood within Milton Keynes, but which could also benefit other hospices and end of life care providers throughout the UK.

How will I undertake the research?

Case studies are really useful in research, especially in health and social care so I will be doing a case study of Willen Hospice. This means getting information from lots of different sources including patients, professionals and the local community. I will do this by using different methods including interviews, surveys and focus groups. The survey has 10 questions which can be completed on email or by completing a paper copy and returning in an SAE to myself.

Why am I being asked to take part?

I want to hear your views and opinions on end of life and hospice care, and will then bring all the different voices together to see what themes emerge. Your voice is important.

Will the information I collect remain confidential?

Yes. I will not use your name in any write up of my research, and your views and contributions will be treated totally confidentially, unless it is felt there is a safeguarding

issue related to what has been disclosed. All materials will only be discussed with my supervisors Dr Sam Murphy and Dr Kerry Jones (contact details below). All contributions will be anonymized, all identifiable material will be destroyed no later than 6 months after participation, and my notes will be securely stored at all times. The anonymised data will be stored and may be used for further research in an open access environment, and there will be no identifying material within it. All information will be handled in accordance with the Data Protection Act 1998.

Can I leave the research?

Yes. You are free to leave the research without reason, at any time, if you no longer wish to take part throughout the data collection stage. If you choose to leave the research before I begin analysing the information which will happen after the main data collection stage, then all of the information you have given me will be destroyed, unless you consent to your information being used in this study. Once data analysis has begun the data will be anonymised and so it will not be possible to remove this anonymised data from the study.

Will there be any risks associated with me taking part?

I do not anticipate that there will be risks associated with this research, however the subject matter may be quite sensitive and could be upsetting at times. If you feel you would like to talk to someone about this, support can be arranged through Willen Hospice. Choosing to take part will not affect your current or any future employment in any way. I shall be happy to discuss anything at any time during the research. My contact details are on this information sheet.

How will the research be used in future?

Research results will be written up for my PhD thesis, and may be published in academic journals and used for educational purposes. No individual will be identifiable, and anonymised data will be stored for possible future research projects in an open research environment.

More information:

Please contact me if you would like to discuss any aspect of this research or require any further information. My e-mail and phone number are at the top of this sheet.

If you want to talk to someone else about this research from The Open University, you can contact the Director of Postgraduate Studies: **Dr Lindsay O'Dell, Faculty of Health and Social Care, The Open University, Walton Hall, Milton Keynes, MK76AA**
Many thanks for considering this request.

Zana Saunders

Consent for Involvement in the
Hospice Care in Milton Keynes Research Project

Name of Project Researcher: Zana Saunders

I would be grateful if you could please read the following and then sign at the bottom – thank you

Please initial box

I confirm that I have read and understood the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered to my satisfaction.

I understand that my participation is voluntary and that I can withdraw at any time up to the end of the data collection stage without giving any reason.

I understand my contributions will be stored securely in line with the Data Protection Act 1998

I have been assured that my confidentiality will be protected as specified in the information sheet.

I agree that the anonymized information that I provide can be used for educational or research purposes, including publication, for any future study that has received ethical approval.

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Name of participant   **Date**   **Signature**

_____   _____   _____

Name of researcher   **Date**   **Signature**

A Qualitative Case Study exploring Perspectives

of End of Life Care in Milton Keynes: Survey

This survey has been designed to enable your thoughts and perspectives on end of life care for the community of Milton Keynes.

There are no right or wrong answers; the questions are designed to enable you to share what you think! Please write whatever you feel is relevant and important to you in the boxes provided.

All information is to be stored anonymously and securely within the Open University data systems and will be retained for research purposes. The only identifiable data requested is that relating to your situation (work, volunteering, community etc). This is in order to see if there are any similarities /differences depending on people's background.

Please do try and fill in every question as this will enable stronger analysis of the results.

A consent form is also included which needs to be included. This will be kept separate to your survey so no identification is possible.

Once complete please return in the prepaid envelope provided.

Many thanks for your agreement in taking part in this research!

Zana Saunders, PhD Researcher, The Open University

Please tick which box is most relevant to you:

☐ Member of staff within a nursing home for older people

☐ Member of staff within a residential home for older people

☐ Member of staff within a prison

☐ Member of staff within a hospice

☐ Member of staff within a hospital

☐ Member of staff/volunteer within a charity supporting people with learning disabilities

☐ Member of staff within a GP practice

☐ Member of staff/volunteer within a charity supporting the homeless

Please write your answers clearly in the spaces provided. Please do not

feel you need to fill all the boxes!

What does end of life care mean to you?

What does hospice care mean to you?

Do you think there is a difference between end of life care and hospice care?

If so, please explain the difference

What patients receive hospice care?

What patients receive end of life care?

How do people in Milton Keynes who need end of life and/or hospice

care access it?

Explain how you feel end of life care is delivered in Milton Keynes

Explain how you feel hospice care is delivered in Milton Keynes

Thinking about the local hospice, please tell me your views on its place

and presence within the local community

And finally, still thinking about the local hospice, is there anything you

feel the hospice could do to improve in any way?

Some questions for our demographics…

Your Gender   _____

Age: 18-25   ☐   26-40   ☐

              41-55   ☐   56+   ☐

Your ethnicity   _____

Hospice Care Research Project
Interview Topic Guide

1. Introduction

Can you tell me about your journey, how you came to be referred through to the hospice/unit at MKUH/other provider? Medical history, diagnosis,

2. Can you tell me a bit about the care and support you have been receiving?

Consider Social/Emotional/Spiritual/Medical

Thinking about non-medical needs, is there support for you? What would you like to have?

3. What does END OF LIFE CARE mean to you?

Have you heard that phrase before, what does it mean?

4. How would you describe a Hospice?

What kind of care do they deliver? What do you know about Willen Hospice in Milton Keynes?

5. In your opinion what are the differences between hospice care and end of life care?

Is there a difference?

6. What patients receive end of life care?

Can they be defined? Is it for everyone?

7. What patients receive hospice care?

Do you know anyone who has been involved with Willen hospice either as patient or family member or other connection?

8. How do you think people in Milton Keynes who need it, access end of life or hospice care?

Referrals?

9. How do you think end of life care is delivered in Milton Keynes?

Access, who delivers

10. Explain how you feel hospice care is delivered in Milton Keynes?

11. Thinking about the local hospice, what are you views on its place and presence within the local community?

Media etc

12. Do you think the hospice could improve in any way?

Its ok to have ideas and comments about this.

13. Anything else you want to tell me about end of life care and hospice care?

Focus Groups: Semi Structured Proposed Questions

- What does end of life care mean to you?

- What does hospice care mean to you?

- How would you describe any differences between end of life care and hospice care?

- Who do you think end of life care is for?

- What patients do/should receive hospice care?

- How do people in Milton Keynes access care when they are diagnosed with a life-limiting condition?

- Explain how you feel end of life care and hospice care is delivered in Milton Keynes?

- What are your views on the place and presence of the local hospice within Milton Keynes?

- How do you think the hospice could improve in what it does?

During the focus groups, participants will be encouraged to engage in the vignette activity

discussing each character and whether they would/should access hospice care, and how.

This is to encourage participants to answer the questions above.

Appendix 10

Derek is a 54 year old Catholic man from Bletchley with diagnoses of diabetes and heart failure

Joelle is a 49 year old Somalian refugee from Netherfield with a diagnosis of pancreatic cancer
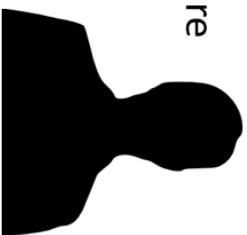
Annalise is a 26 year old woman from the traveller community near Milton Keynes who has a diagnosis of stomach cancer

Simeon is a 51 year old homeless man living in Milton Keynes with a diagnosis of end stage liver disease

Hassan is a 76 year old Muslim man from Wolverton with advanced stage dementia

Patrick is a 68 year old man who is a prisoner at Milton Keynes prison with a diagnosis of lung cancer

Jarod is a 44 year old man with 3 children from Stony Stratford with a diagnosis of Motor Neurone Disease

Alice is a 74 year old lady from Conniburrow with diagnoses of learning disabilities and Parkinson's disease

Valerie is a 67 year old lady from Woolstones with bipolar disorder and Chronic Obstructive Pulmonary Disorder (COPD)

Nahida is a 36 year old lady from Pakistan living in Walnut Tree with a diagnosis of Multiple Sclerosis

Arnav is a 76 year old Hindu man from Stantonbury with a diagnosis of acute stroke and is registered blind

Ruth is an 84 year old Scottish lady living in a care home in Neath Hill with diagnoses of Parkinsons and Alzhemiers Disease
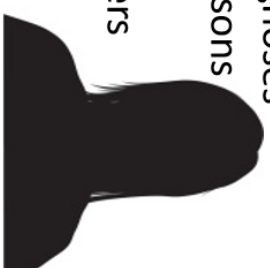
Appendix 11

Analysis of Questionnaire Data: Code and Theme Map
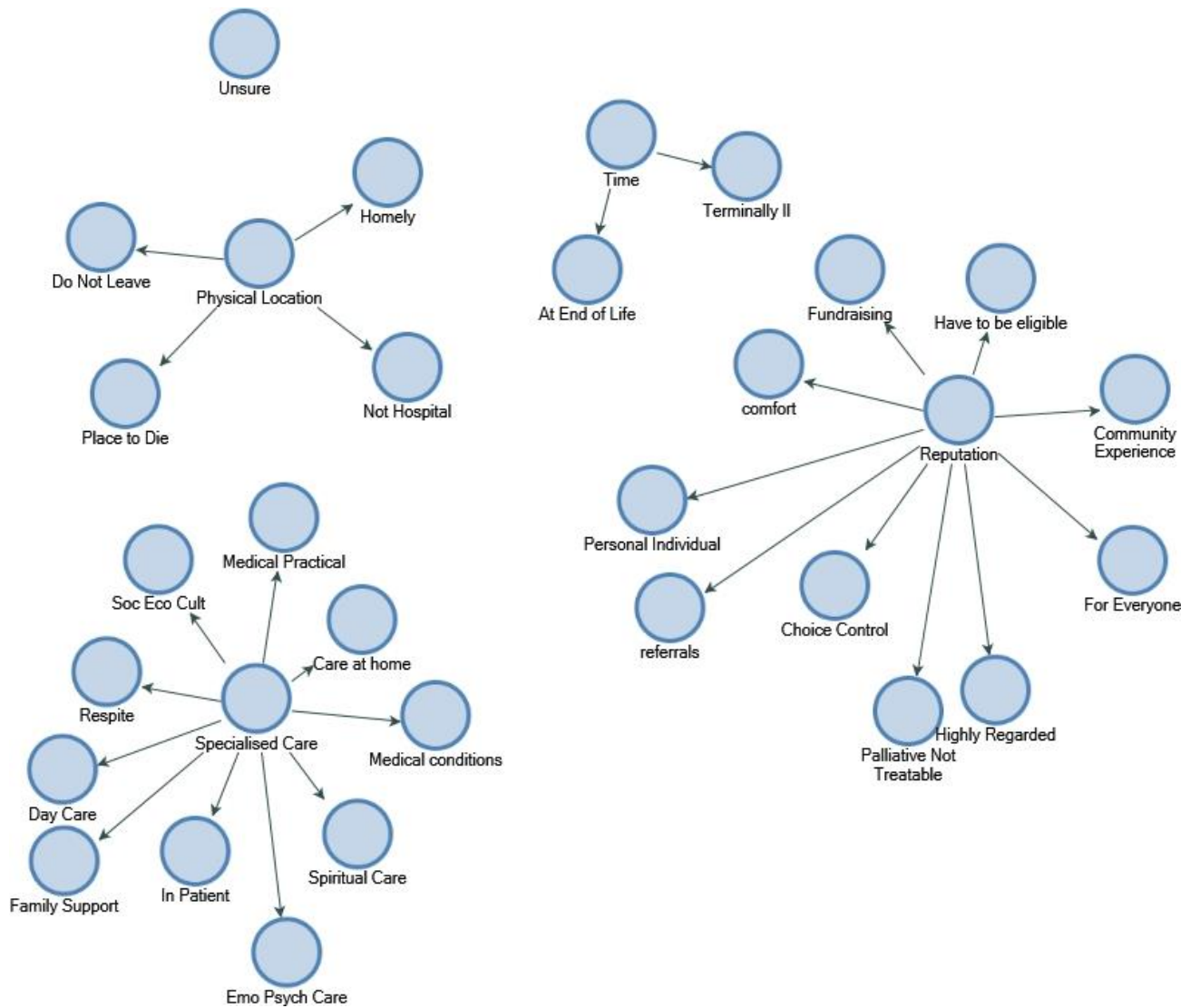
Appendix 12

Analysis of Focus Group Data: Code and Theme Map
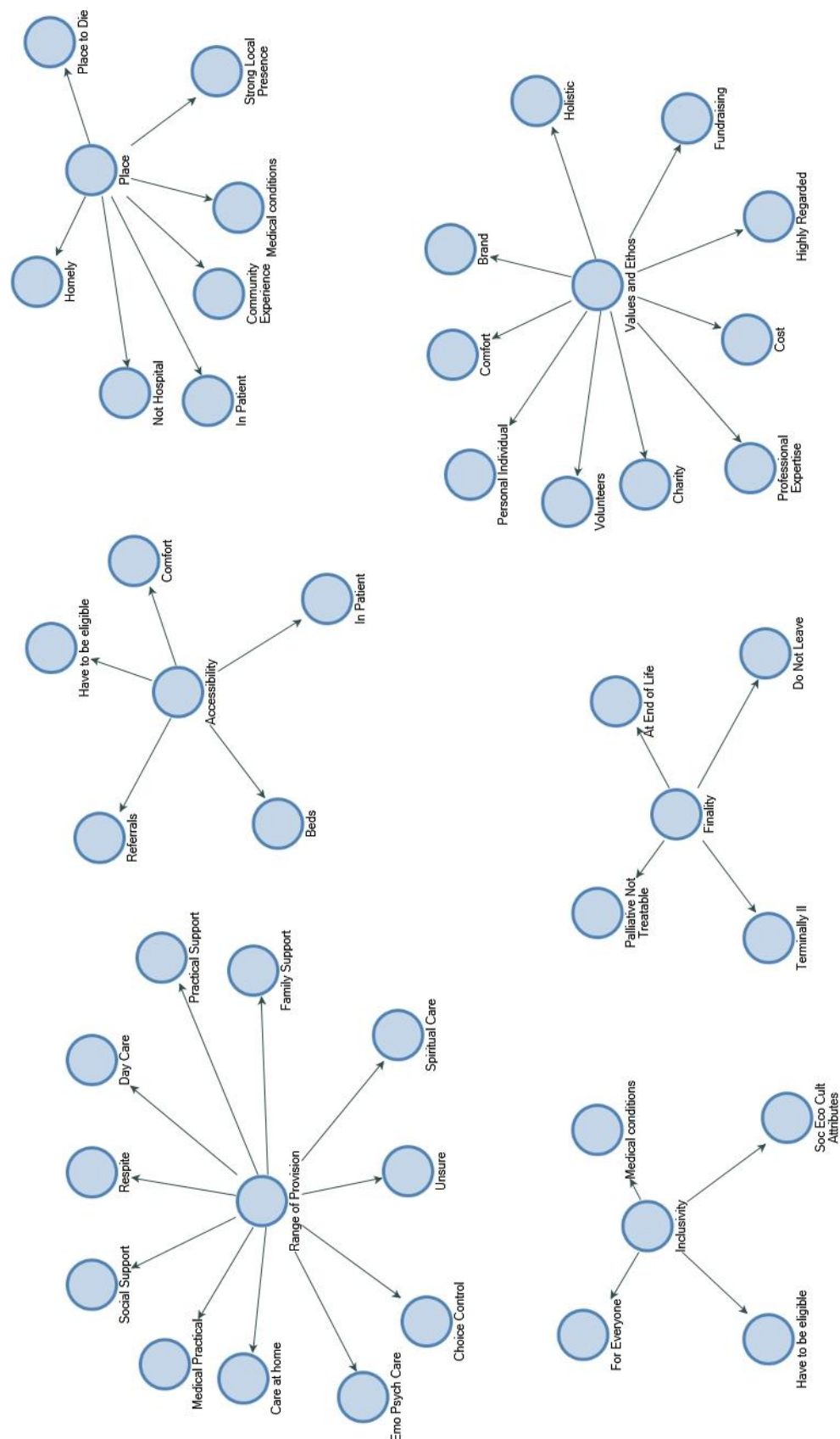
Appendix 13

Analysis of Interview Data: Code and Theme Map

Appendix 14
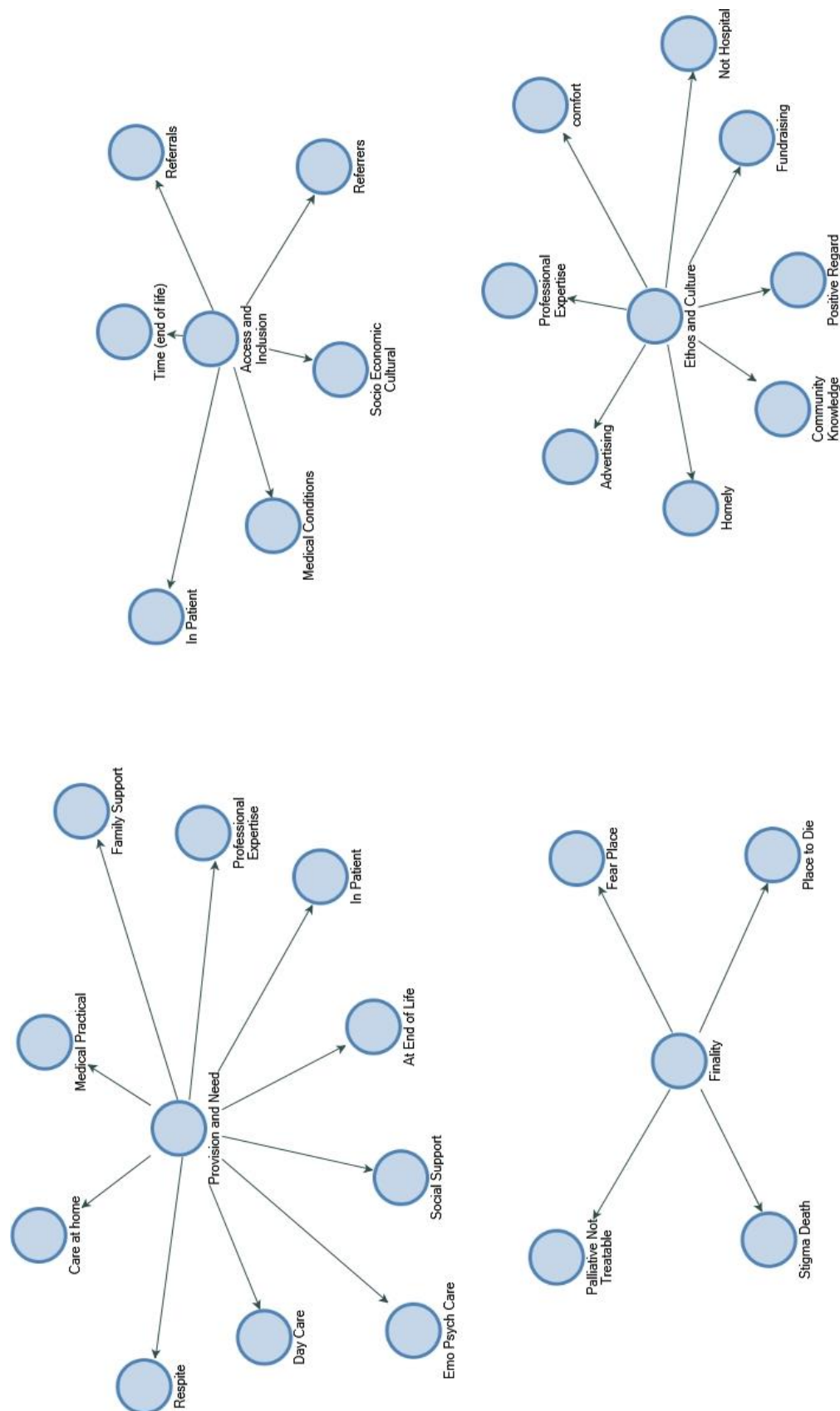
Mrs Zana Saunders
The Open University
Walton Hall
Milton Keynes
MK76AA

16 May 2018

Dear Mrs Saunders

HRA and Health and Care

Study title:	**The Unique Case of Milton Keynes and its Hospice Provision: Perspectives of a Community**
IRAS project ID:	**231998**
REC reference:	**18/LO/0525**
Sponsor	**The Open University**

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW)**

Approval has been given for the above referenced study, on the basis described in the

application form, protocol, supporting documentation and any clarifications received. You

should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in

England and Wales? You should now provide a copy of this letter to all participating NHS

organisations in England and Wales*, as well as any documentation that has been updated

as a result of the assessment.

*'In flight studies' which have already started an SSI (Site Specific Information) application for NHS organisations in Wales will continue to use this route. Until 10 June 2018, applications on either documentation will be accepted in Wales, but after this date all local information packs should be shared with NHS organisations in Wales using the Statement of Activities/Schedule of Events for non-commercial studies and template agreement/ Industry costing template for commercial studies.

Following the arranging of capacity and capability, participating NHS organisations in

England and Wales that are **recruiting sites** should **formally confirm** their capacity and

capability to undertake the study. How this will be confirmed is detailed in the "*summary of*

assessment" section towards the end of this letter. You should then work with each

organisation that has confirmed capacity and capability and provide clear instructions when

research activities can commence.

Participating NHS organisations in England and Wales that are **other sites <u>will not</u>** be

required to formally confirm capacity and capability before you may commence research

activity at site. As such, you may commence the research at each organisation 35 days

following sponsor provision to the site of the local information pack, so long as:

  ☐ You have contacted participating NHS organisations (see below for

  details) ☐ The NHS organisation has not provided a reason as to why they

cannot participate ☐ The NHS organisation has not requested additional time to confirm.

You may start the research prior to the above deadline if the site positively confirms that the research may proceed.

If not already done so, you should now provide the [local information pack](#) for your study to your participating NHS organisations. A current list of R&D contacts is accessible at the [NHS RD Forum](#) [website](#) and these contacts MUST be used for this purpose. After entering your IRAS ID you will be able to access a password protected document (password: **Spring24**). The password is updated on a monthly basis so please obtain the relevant contact information as soon as possible; please do not hesitate to contact me should you encounter any issues.

Commencing research activities at any NHS organisation before providing them with the full local information pack and allowing them the agreed duration to opt-out, or to request additional time (unless you have received from their R&D department notification that you may commence), is a breach of the terms of HRA and HCRW Approval. Further information is provided in the "*summary of assessment*" section towards the end of this document.

It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up

your study. Contact details of the research management function for each organisation can

be accessed [here](#).

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?
HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved

administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of

these devolved administrations, the final document set and the study wide governance

report (including this letter) has been sent to the coordinating centre of each participating

nation. You should work with the relevant national coordinating functions to ensure any

nation specific checks are complete, and with each site so that they are able to give

management permission for the study to begin.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern

Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with

your non NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The document "*After Ethical Review – guidance for sponsors and investigators*",

issued with your REC favourable opinion, gives detailed guidance on reporting expectations

for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics, and is updated in the light of

changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?

You should work with the applicant and sponsor to complete any outstanding arrangements

so you are able to confirm capacity and capability in line with the information provided in

this letter.

The sponsor contact for this application is as follows:

Name: Zana Saunders

Tel: 01908 652306

Email: Zana.saunders@open.ac.uk

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details

are below.

Your IRAS project ID is **231998**. Please quote this on all correspondence.

Yours sincerely

Natalie Wilson

Assessor

Email: hra.approval@nhs.net

Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England

and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with

relevant standards. It also provides information and clarification, where appropriate, to

participating NHS organisations in England and Wales to assist in assessing, arranging and

confirming capacity and capability.

Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments

Section	Assessment Criteria	Compliant with Standards	Comments
2.1	Participant information/consent documents and consent process	Yes	Minor amendments have been made to PIS documents post-REC to ensure conformity to HRA Standards.
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	This is a non-commercial, multicentre study taking place in the NHS.

Two Statement of Activities documents have been submitted. A Statement of Activities will act as the agreement between sponsor and recruiting sites.

Although formal confirmation of capacity and capability is not expected of all or some organisations participating in this study, and such organisations would therefore be assumed to have confirmed their capacity and capability should they not respond to the contrary, we would ask that these organisations pro-actively engage with the sponsor in order to confirm at as early a date as possible. Confirmation in such cases should be by email to the CI and Sponsor confirming participation based on the relevant Statement of Activities and information within this letter. |
| **Section** | **Assessment Criteria** | **Compliant with Standards** | **Comments** |

4.2	Insurance/indemnity arrangements assessed	Yes	Where applicable, independent contractors (e.g. General Practitioners) should ensure that the professional indemnity provided by their medical defence organisation covers the activities expected of them for this research study
4.3	Financial arrangements assessed	Yes	Sponsor is not providing funding to participating NHS organisations
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	Minor amendments have been made to PIS documents post-REC to ensure conformity to HRA Standards.
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion received for applicable studies	Yes	No comments
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	
6.3	Devices – MHRA notice of no objection received	Not Applicable	
6.4	Other regulatory approvals and authorisations received	Not Applicable	

Participating NHS Organisations in England and Wales

This is a non-commercial, multicentre study. There are two site-types involved in the research. Activities at recruiting sites will include the possible identification of patient participants, the identification of staff participants, as well as a possible location for completing any staff surveys.

Activities at other sites will include the practice manager passing copies of the survey onto relevant staff and the completion the survey.

The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. Where applicable, the local LCRN contact should also be copied into this correspondence.

If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS or on the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net, or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.

Principal Investigator Suitability

A Principal Investigator (PI) is expected at recruiting sites. Neither a PI nor a Local Collaborator (LC) is expected at other sites.

GCP training is not a generic training expectation, in line with the HRA/HCRW/MHRA statement on training expectations.

HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken
As this study is taking place in GP practices we expect you contact the primary care management function to follow their local process. Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales to aid study set-up.
The applicant has indicated that they <u>intend</u> to apply for inclusion on the NIHR CRN Portfolio.

Human Research Ethics Committee (HREC)

From	Professor Louise Westmarland
	The Open University Human Research Ethics Committee

Email	louise.westmarland@open.ac.uk
Extension	(6) 52462

To	Zana Saunders

Project title: Perspectives of Hospice Care Services in Milton Keynes:

An In-depth Multi-Method Qualitative Study

HREC ref   HREC/2768/Saunders

Memorandum

Date application submitted: 04/01/2018

Date of HREC response: 01/03/2018

This memorandum is to confirm that the research protocol for the above-named research

project, as submitted for ethics review, has been given a favourable opinion by the Open

University Human Research Ethics Committee.

Please note the following:

1. You are responsible for notifying the HREC immediately of any information received by
   you, or of which you become aware which would cast doubt on, or alter, any
   information contained in the original application, or a later amendment which would
   raise questions about the safety and/or continued conduct of the research.

2. It is essential that any proposed amendments to the research are sent to the HREC for
   review so they can be recorded and where required, a favourable opinion given prior
   to any changes being implemented (except only in cases of emergency when the
   welfare of the participant or researcher is or may be affected).

3. Please include your HREC reference number in any documents or correspondence. It is
   essential that it is included in any publicity related to your research, e.g. when seeking
   participants or advertising your research so it is clear that it has been reviewed by
   HREC and adheres to OU ethics review processes.

4. You are authorised to present this memorandum to outside bodies such as NHS
   Research Ethics Committees in support of any application for future research
   clearance. Also, where there is an external ethics review, a copy of the application and
   outcome should be sent to the HREC.

5. OU research ethics review procedures are fully compliant with the majority of grant
   awarding bodies and where they exist, their frameworks for research ethics.

6. At the end of your project, you are required to assess your research for ethics related
   issues and/or major changes. Where these have occurred you will need to provide the
   Committee with a HREC final report to reflect how these were dealt with using the final
   report template on the research ethics website
   http://www.open.ac.uk/research/ethics/human-research/full-review-process - final
   report

Best regards

Professor Louise Westmarland

The Open University Human Research Ethics Committee

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